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TITLE: Spiritual-Based Intervention for African American Women with Breast Cancer

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<b>14. ABSTRACT</b> Because social support has been shown to have value in decreasing morbidity and possibility in increasing length of survival in cancer patients, the objectives of the study are: 1) to utilize a network of oncology services, churches, and community organizations to recruit African American women diagnosed with breast cancer for project participation; 2) to implement the spiritual-based intervention; 3) to assess the efficacy of the intervention to positively impact treatment-related outcomes; and 4) to refine the intervention for broader dissemination. The intervention involved an experimental/control group design approach. The experimental support group (intervention group) received the Spiritual-based support intervention. There were two control groups: control group A included participants in a traditional support group model and control group B included individuals who received the standard care consisting of no additional structured support. Data were gathered through a pre-test at baseline (T1), a post test at the conclusion of the 7 month intervention (T2), and at a three-month follow-up at the end of the support group sessions (T3). Findings suggest a positive influence of the spiritual support group on mental well-being, with the impact diminishing over time.					
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## **INTRODUCTION**

The research was designed to test a spiritual-based support group intervention for recently diagnosed African American breast cancer patients. It was hypothesized that the women who participated in the spiritual intervention would have a better quality of life, less depression, anger and anxiety, greater use of health promoting behaviors and a higher treatment compliance than the women in the two control groups. The two control groups consisted of 1) a traditional support group therapy and 2) those patients who received standard care with no additional structured support. Pre-test, post-test and follow up surveys were administered to all of the participants. The pre-test provided baseline data from which all the subsequent data was compared and assessed. The post-test was administered at the conclusion of the intervention tests to assess how effective the intervention was on improving the overall quality of life of each participant. Finally, the follow-up survey was administered three months after the end of the sessions to test the long-term effects of the intervention.

## **BODY**

Current data show that African American women have higher rates of mortality once they are diagnosed, even though breast cancer incidence is lower for them than for Caucasian women. African American women experience a 5-year relative survival of 89.6 percent when diagnosed at a localized stage, compared to a 97.4 percent survival for Caucasian women diagnosed at the same stage. Among those diagnosed at the regional stage, 61.2 percent of African American women survive, compared to a 77.4 percent survival among Caucasians (Karmanos Cancer Institute, SEER, 1997). Although a number of

explanations are offered for race differences in mortality, the reasons are not explicitly known. While some of the differences might be related to tumor biology (citation), research also shows that African American women with breast cancer report lower treatment compliance, less use of health promoting behaviors and a lower quality of life (Ashing-Giwa, Ganz & Petersen, 1999) than their Caucasian counterpart. These are factors that may have relevance for race differences in survival and mortality. However, few psychosocial interventions have addressed these issues with African American women with breast cancer.

The diagnosis of breast cancer constitutes a major life crisis that is often accompanied by depression, anxiety, fear, anger, insomnia, appetite and sleep disturbances, impaired concentration, and possible difficulty in maintaining daily activity (Houldlin & Lowery, 1992; Ersek & Ferrell, 1994; Creagan, 1997). A growing body of literature indicates that psychosocial factors such as social support can help women cope and adjust (Speigel, 1990; Helgeson & Cohen, 1996; Maunsell, Brisson & Duchenes, 1995). Fawzy and colleagues reported that malignant melanoma patients who participated in support group sessions demonstrated significant reductions in mood disturbance and used more active coping strategies than patients receiving routine oncologic care (Fawzy, Cousins, Fawzy, et al., 1990). They also reported that the patients in the intervention showed significant differences in immune system function at the 3-month follow-up (Fawzy, Kemeny, Fawzy, et al., 1990). Spiegel (1990) also cites the importance of social support as a form of "social integration" in enhancing quality of life and increasing survival time among breast cancer patients. In his randomized control group study, he found that patients in the

experimental group had fewer phobic responses and half the pain of the control group. In addition, control subjects lived an average of only 18.9 months in comparison to the patients randomized to psychosocial treatment who lived an average of 36.6 months. In another study with lymphoma and leukemia patients, Richardson and colleagues (1990) found that those who were randomly assigned to one of the supportive interventions not only survived significantly longer, but were also more likely to comply with medical treatment than did patients who were assigned to a routine care only condition. Other studies have shown that behavioral interventions resulted in a 50 percent reduction in office visits during the ensuing six months (Hellman, Budd, et al., 1990). Overall, while social support appears to enhance quality of life and possibly extend length of survival in cancer patients, minority women and those living in economically depressed areas tend to have less access to social support and experience greater social isolation than the general population (Freeman, 1995). Few interventions have included African American women or have focused on psychosocial interventions such as spirituality that may be culturally appropriate for this population.

**Spirituality and African Americans.** Prior research shows that African Americans are more likely than Caucasians to use spirituality and religious involvement to cope with adversity (Rosen, 1982; Koenig & Futterman, 1997). In one of the few studies that included African American breast cancer patients, Potts (1996) noted that two major themes emerged: a belief in God as the source of healing, and prayer as instrumental in coping with cancer. Further corroboration of the importance of spirituality and religion among African Americans is provided in focus groups we conducted with African American

and Caucasian breast cancer survivors. The African American women mentioned a greater number of spiritual and religious coping references, irrespective of age and socio-economic status. In addition, many African American women indicated that they relied on spirituality and religious practices such as prayer, meditation and reading the Bible. Caucasian women were more likely to rely on medical and educational sources for dealing with their illness. Spirituality also appeared to influence treatment decision-making. One African American woman said *"I try to have a conversation with Him before I make decisions. God directs me."* Although not generalizeable, these focus group comments were useful in understanding the importance of spirituality in coping with breast cancer and to suggest the need for a Spiritual-based intervention for African American women.

**Definition of Spirituality.** The literature suggests that although spirituality and religiousness are conceptually linked, they are not the same. While religious involvement may relate to specific organizational or denominational beliefs or practices, spirituality encompasses an "affirmation and satisfaction with life and a relationship with God, as well as the perception that one's life has meaning" (Mickley, Soeken, Belcher, 1992). For the purposes of the study, spirituality is defined as "the propensity to find meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. This relatedness may be experienced intrapersonally (as a connectedness within oneself), interpersonally (in the context of others and the natural environment), and transpersonally (referring to a sense of relatedness to the unseen, God, or power greater than the self and ordinary resources)" (Brewer, 1979). Empirical documentation of a link between spirituality and various health outcomes is

increasing (Post-White, Ceronsky, et al., 1996). Studies specifically of breast cancer survivors report that religious beliefs, prayer and meditation emerged as powerful coping forces within their lives (Fredette, 1994) and were the most frequently mentioned factors in helping women and their husbands cope with breast cancer (Northouse, 1989; Creagan, 1997). Despite this evidence, Spiritual-based interventions targeting African American women with breast cancer have not evolved from African American religious institutions or from the broader system of health and social service delivery.

In an effort to address this need, the study attempted to take a well-documented resource in African American communities, spirituality - and to incorporate it into a psychosocial intervention designed to enhance treatment-related outcomes. The intervention was *culturally targeted* to African American women diagnosed with breast cancer. The study included an advisory group of community clergy and breast cancer survivors from various denominations who were involved in its development and implementation. Although the spiritual-based intervention is non-denominational, it is primarily Protestant and Christian, reflective of the vast majority of African Americans

**Conceptual Framework and Hypotheses.** A social support framework provided the context for the study's hypotheses (Wheaton, 1985; Krause and Tran, 1989). Based upon previous social support studies, it is expected that those women receiving the Spiritual-based intervention will have better mental health and quality of life, along with greater health promoting behaviors and treatment compliance than will women who do not participate in the intervention. Four hypotheses are posed: **(H1)** Women in the Spiritual-



based intervention will have less depression, anger and anxiety than women who are in the control groups. **(H2)** Women in the Spiritual-based intervention will have greater overall quality of life than women who are in the control groups. **(H3)** Women in the Spiritual-based intervention will have greater use of health-promoting behaviors than those who are in the control groups. **(H4)** Women in the Spiritual-based intervention will have greater treatment adherence in comparison to those who are in the control groups.

**Objectives.** The study had four objectives: 1) To utilize a network of oncology services, churches, and community organizations to recruit African American women with breast cancer for participation in a support group intervention based on spirituality; 2) To implement the Spiritual-based intervention; 3) To assess the efficacy of the intervention to positively impact treatment-related outcomes ; and 4) To refine the intervention for broader dissemination.

**Methods.** The research design involved an experimental/control group approach in which the experimental group (**intervention group**) received the Spiritual-based intervention. **Control group A** included participants in a traditional support group model and **control group B** included individuals who received standard care consisting of no additional structured support. It was planned that data would be collected from participants at three times. The pretest interview occurred prior to the beginning of the intervention (T1) with a post-test within two weeks of the conclusion of the intervention (T2) and second post-test (T3) 3 months after the intervention to investigate the extents to which there are enduring effects.

**Content of the Intervention.** Pilot work had been done to develop a Spiritual-based social support group intervention designed to provide educational and emotional support to African American women with breast cancer. The basic content was derived from resources developed by the Association for Spiritual, Ethical, and Religious Values in Counseling, the American Cancer Society, the Blue Cross Blue Shield Foundation of Southeast Michigan, Karmanos Cancer Institute, the National Cancer Institute's Cancer Information Service and the National Coalition for Cancer Survivorship. For the Spiritual-based support intervention, the content was placed within a **nondenominational** context that begins and ends with prayer. In addition, the Spiritual-based support intervention uses various spiritual principles (one's awareness of belonging, meaning and purpose, acceptance, values and awe) that are integrated into the educational topics. The focus of utilizing these spiritual principles was to help access and determine the internal and external spiritual resources available to the group members to assist them in: 1) coping with their disease and the changes it brought in their lives and in 2) achieving new goals which they have set for themselves. The Spiritual-based intervention was originally devised for 6 group sessions, but as the result of the initial development and testing with a small group (n=8), a 7<sup>th</sup> session has been added. The first group session consists of an introductory discussion to begin to build trust and to familiarize everyone with each other and the purpose of the group. The second session dealt with issues of grief that the group members may experience during their treatment, including the discussion of the stages of grief, mechanisms for handling depression, and anger. The third session focused on the development of healthy lifestyles during treatment and beyond, including coping with the

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## **INTRODUCTION**

The research was designed to test a spiritual-based support group intervention for recently diagnosed African American breast cancer patients. It was hypothesized that the women who participated in the spiritual intervention would have a better quality of life, less depression, anger and anxiety, greater use of health promoting behaviors and a higher treatment compliance than the women in the two control groups. The two control groups consisted of 1) a traditional support group therapy and 2) those patients who received standard care with no additional structured support. Pre-test, post-test and follow up surveys were administered to all of the participants. The pre-test provided baseline data from which all the subsequent data was compared and assessed. The post-test was administered at the conclusion of the intervention tests to assess how effective the intervention was on improving the overall quality of life of each participant. Finally, the follow-up survey was administered three months after the end of the sessions to test the long-term effects of the intervention.

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**Conceptual Framework and Hypotheses.** A social support framework provided the context for the study's hypotheses (Wheaton,1985; Krause and Tran,1989). Based upon previous social support studies, it is expected that those women receiving the Spiritual-based intervention will have better mental health and quality of life, along with greater health promoting behaviors and treatment compliance than will women who do not participate in the intervention. Four hypotheses are posed: **(H1)** Women in the Spiritual-

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**Objectives.** The study had four objectives: 1) To utilize a network of oncology services, churches, and community organizations to recruit African American women with breast cancer for participation in a support group intervention based on spirituality; 2) To implement the Spiritual-based intervention; 3) To assess the efficacy of the intervention to positively impact treatment-related outcomes ; and 4) To refine the intervention for broader dissemination.

**Methods.** The research design involved an experimental/control group approach in which the experimental group (**intervention group**) received the Spiritual-based intervention. **Control group A** included participants in a traditional support group model and **control group B** included individuals who received standard care consisting of no additional structured support. It was planned that data would be collected from participants at three times. The pretest interview occurred prior to the beginning of the intervention (T1) with a post-test within two weeks of the conclusion of the intervention (T2) and second post-test (T3) 3 months after the intervention to investigate the extents to which there are enduring effects.

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side-effects of treatment, proper exercise and maintaining an appropriate diet. The topic of the fourth session centered on building good communications skills, between the participant and her doctors, family and support group. The fifth session focused on stress management in which participants learned about its impact on their mental and physical health and acquired effective methods of managing the changes in their life. In the sixth session, the group explored the concepts of intimacy, self-esteem and sexuality and to uncover the impact of breast cancer and its treatments on those aspects of their lives. The seventh session focused on goal setting and dealt with closure issues. This session emphasized the importance of balance in achieving goals and assisted the group members in learning the necessary steps for achieving their goals and moving on to the next series of goals in their lives.

To be noted, the Spiritual-based support group and the traditional support group (control group A) received the same educational and informational content. However, the Spiritual-based intervention provided the information within a spiritual context. Each session had specific objectives. At the beginning of each session, the lead facilitator in both the intervention and control group A asked if any members had issues that need to be addressed. If so, the facilitators guided the discussion, providing assistance to members in finding resolution. Afterwards, the lead facilitator addressed the topic for the evening, using the appropriate session outline and educational tools. The sessions were designed to allow ample time for questions, discussion and feedback from the members. Various exercises were included in each session to ensure participation from all participants.

**Recruitment of Study Participants:** The study began in Detroit, but was moved to Newark New Jersey due to the PI's relocation from Wayne State University of the University of Medicine and Dentistry of New Jersey. In Detroit, the primary sources of recruitment included the Detroit Medical Center hospitals, St. John's Hospital and the Karmanos Cancer Institute; all of which served a large African American patient base. Flyers and announcements were sent to more than 400 churches. Radio announcements were prepared and the PI took part in several radio talk programs.

When the project was relocated to New Jersey, several difficulties were encountered. The relocation necessitated requesting and receiving approvals for the transfer of the grant, establishing a project infrastructure and building relationships in the community for participant recruitment. To be noted, there were innumerable difficulties in getting the funds transferred from Wayne State University to the University of Medicine and Dentistry of New Jersey (UMDNJ). This process involved Wayne State preparing a final financial report and necessitated numerous phone calls and requests from the PI and other UMDNJ personnel. We also had to obtain the DOD sign-off on the transfer which occurred at a time when there were several changes in contact persons at DOD. In addition, there were numerous procedures and processing of necessary paperwork at UMDNJ. The transfer of the grant took more that two years to execute.

After the transfer was processed, there was a delay in hiring Project Staff because a coordinator could not be hired until the monies were officially available at the University. In addition, the position had to be officially established through Human Resources, advertised and candidates interviewed in accordance with University procedures. This



was another lengthy, time-consuming process. Finally, we were able to hire a staff person (Tamara Henry) who was able to make some connections in the community as part of the recruitment process. However, her employment did not work out well and she separated from University service five months later. Again, we advertised the position and interviewed candidates. Dr. Joanne Fagan was subsequently hired to serve a project coordinator.

Obtaining IRB approval associated with the relocation was another arduous process which held up the recruitment of study participants. Even though the project protocols had been reviewed and approved by DOD and the Wayne State University IRB, we were required to go through the entire process again. This process was a much extended one, involving several levels of approval at both the UMDNJ IRB and DOD. There were several instances where agreement was lacking between the UMDNJ IRB and DOD on either the protocol, study consent or study forms. These disagreements had to be reconciled before the study could go forward. Again, this was a very laborious and time consuming effort.

As part of the relocation, it was necessary to build relationships in the greater Newark, New Jersey community to facilitate the recruitment of study volunteers. Establishing relationships in the community was viewed as an important aspect of subject recruitment. An Advisory Committee was identified comprised of breast cancer survivors and local clergy. The Advisory Group met and support group facilitators were also identified. A variety of recruitment strategies were implemented including: 1) distribution of study recruitment flyer by staff at local cancer centers (n=6); 2) placement of study recruitment

flyer at local pharmacies (n=30); 3) placement of study recruitment flyers throughout UMDNJ; 4) placement of study recruitment flyers in local hair salons (n=169); 5) distribution of study information to health and women's ministries of local churches (n=17); and 6) distribution of a press release. All of these methods yielded minimal results (3 calls from potential subjects, 2 of which were eligible and agreed to participate). We finally began to recruit subjects directly from the Oncology Department at UMDNJ – NJ Medical School when they came for a treatment or follow-up visit. Prior to talking with the patient, the Cancer Center staff person would discuss the project with them and ask if they were willing to talk with us. If they said yes, we screened them for eligibility. Over a five month period 11 women were screened for eligibility of which 8 were eligible and agreed to participate. Because of the slow pace of recruitment we realized that we would not be able to meet the goal of recruiting and randomizing 54 women.

**Inclusion & Exclusion Criteria.** To be included in the study, women must have been within 24 months of initial breast cancer diagnosis. The 24 month period was used because of the PI's prior experience with breast cancer patients had demonstrated that patients often do not seek a support group at the time of diagnosis; instead, many join support groups after treatment has ended at a time when support from their natural support networks (families, friends, etc.) has diminished or when patients discover that their support needs can no longer be met by their personal support network. Other criteria included being diagnosed at stage I, II or III with no history of a recurrent disease and being between the ages of 40 - 65. Women were excluded if they had a history of diagnosed mental illness, stage IV or recurrent breast cancer, and suffered from more

than one major co-morbid condition. This last criterion posed a barrier to recruitment, as project staff encountered women who met all but this criterion. In future studies, the presence of co-morbidities among African American women has to be taken into consideration.

Participants were also screened using a modified short form of the spirituality index (Post-White et al., 1996). This excluded persons who had no personal conceptualization of spirituality, e.g. atheistic or agnostic individuals. The screening measure consists of six items which ascertain level of agreement on a four point Likert scale ranging from "0" to "3". Participants who score "1" or less on three or more items were excluded from participation in the study.

**Delivery of the Intervention.** Initially, it was projected that the intervention would be in delivered in 3 rounds. but with the difficulties in recruitment the study concluded with two rounds., with the first round beginning in month 6 of year one. Both the intervention and control group A generally met for 90 minutes once per month for 7 consecutive months. After the first round, this was revised such that the seven sessions were held every other week. Given that group meetings were held during evening hours, the facilitators provided members with a light meal prior at the start of each session. The sessions were held at the Cancer Center location and at St. John hospital. While the intervention group facilitators encouraged spiritual and religious expression, these were not encouraged by the facilitators in control group A. However, such expressions were allowed if the group members initiated such action. Each group (intervention and control group A) was conducted by two trained facilitators. The training of facilitators was provided by

consultants Mary Worrell and Denise Ballard who are experts on breast cancer biology and treatment and group facilitation, respectively.

Data Collection. As previously mentioned only two rounds of intervention testing were held in light of the PI's relocation from Wayne State University of the University of Medicine and Dentistry of New Jersey and the difficulties encountered in recruitment. The outcome measures were assessed across T1, T2 and T3 focused on: 1) depression, anxiety, anger, 2) quality of life, 3) use of health promoting behaviors and 4) treatment compliance. Two measures of mental health were included: the Profile of Mood States (POMS) and the Center for Epidemiologic Studies Depression Scale (CESD). As a measure of affective states for individuals with illness, the POMS includes 65 items that tap anxiety, anger and depression and has been validated on minority populations and women with breast cancer (Fawzy, et al., 1990). The CESD is a 20 item self report measure reflecting the major components of depressive symptomatology (depressed affect, somatic complaints, well-being and interpersonal domains) (Radloff, 1977). It has high internal consistency and has previously been used with African American populations (Gary, Brown, et al., 1989). The quality-of-life measure was the Functional Assessment of Cancer Therapy Scale (FACT-B: Cella et al., 1993). The FACT-B consists of 34 statements representing six major areas of concern: physical well-being, social/family well-being, relationship with doctor, emotional well-being, functional well-being and additional concerns. Responses to statements are graded on a 5 point Likert-type scale from "0" not at all to "4" very much. It has a test-retest reliability of .92. and an coefficient alpha of .89. To assess health promoting behaviors, the Health Promoting Life Style Profile

(HPLP:Walker, Sechrist & Pender, 1987) was used. The scale's four dimensions of health responsibility, exercise, nutrition, and stress management have been used on populations of varied age groups, race/ethnicity and socio-economic statuses; they demonstrate good internal consistency with alphas ranging from .702 to .814. Treatment compliance was measured by items from the Rehabilitation Compliance Scale (Rheiner, 1994). Demonstrating good reliability, the scale assesses the extent to which the patient feels she has followed physician's recommendations.

In addition, data were collected on socio-demographic background characteristics, religious involvement, other major life stressors, other sources of social support for dealing with their breast cancer, cancer background and history. To assess participants' level of spiritual well-being, the Spiritual Well-being Scale by Ellison (1983) was used. Previously used with minority populations, it consists of 20 items presented in a six-point Likert-type format. It has two major components: a religious well-being subscale and an existential well-being subscale. Test-retest reliability is .86 with an alpha of .88. The instrument items are listed in the Appendix II; they were selected because of their psychometric properties and their use with minority and/or illness populations. The two post-test interviews were only slightly shorter and covered changes in the outcomes measures as well as changes in socio-demographic and background variables, cancer history, social support, major stressors and religious involvement. Each participant received \$70 at the end the intervention period.

**Data Management and Analysis.** The data were analyzed utilizing the Statistical Package for the Social Sciences (SPSS-X). The data analysis focused on testing each of the 4

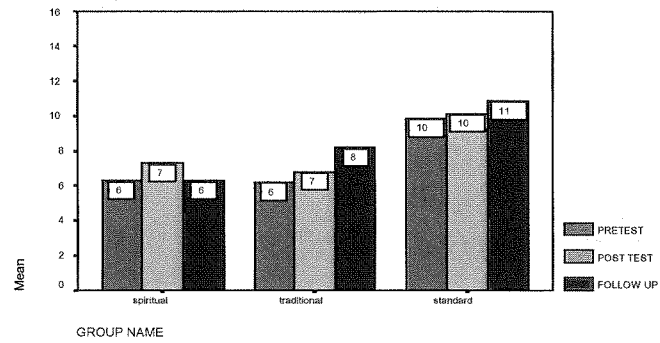
hypotheses related to changes in outcome variables. Comparisons were made between control and intervention group with regard to outcome variables; however because of the small numbers it was difficult to obtain levels of significance for many of the comparisons. Evaluative feedback was also obtained on the project's implementation and resulted in modifications to the intervention.

### **Key Research Accomplishments and Reportable Outcomes**

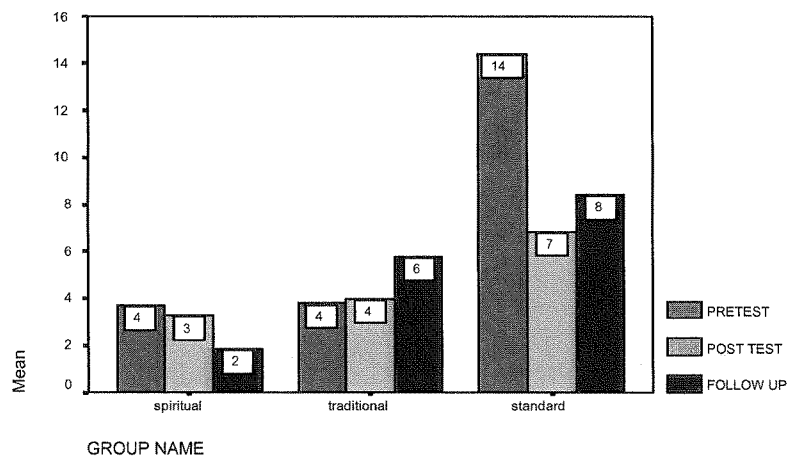
After randomization, data from the two rounds of the intervention resulted in the following distribution in the three study arms: traditional (n=10), spiritual (n=17) and standard care (n=4). Retention was highest in the spiritual group, followed by the traditional support group, and lowest among women in the standard care. Out of 31 participants in the intervention, 40 percent were married and 40 percent were diagnosed at Stage II; 76 percent were Protestant, 8 percent were Catholic, with the remaining not providing their religious affiliation.

The findings for the mental health measures are given in Figures 1-3. Across the three measures, anxiety, depression and anger, the spiritual group appeared to fare better. There was an increase in anxiety from pre-test to post-text, however, the follow up assessment indicated a decrease in anxiety and anger. The traditional and the control group, reports of their well-being generally declined in mental-well being. Depression and anxiety increased over time, although there was a decrease in reported anger.

**FIGURE 1**  
**ANXIETY FACTOR**

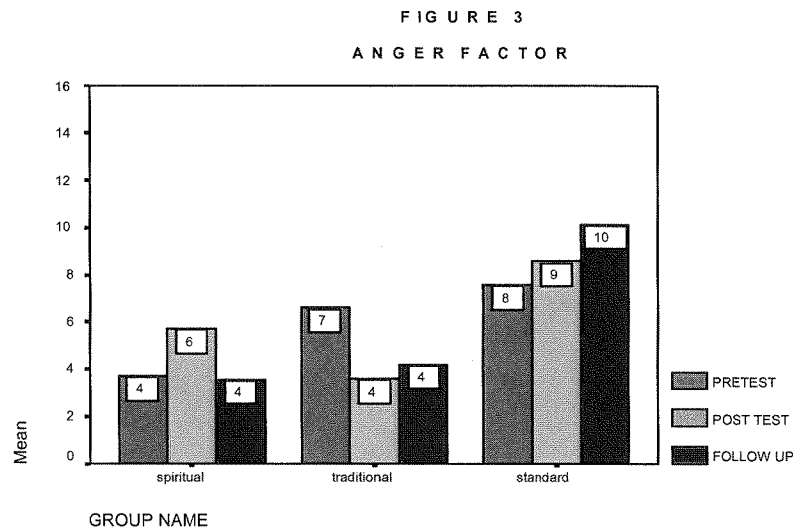


**FIGURE 2**  
**DEPRESSION FACTOR**



To be noted, better attendance was documented for the spiritual group in comparison to

the traditional support group. It was also noted that the spiritual group viewed having breast cancer as a journey not a burden. Results also indicated that there existed greater bonding and emotional support among the women in the spiritual group in comparison to the women in the traditional support group. Now, that the basic content and structure have been devised, we need to apply it to a larger group of women to test the efficacy of the spiritual-based support for enhancing treatment-related outcomes for African American women with breast cancer.



Overall, the spiritual group participants appeared to be more responsive to participating in the support group than are those in the traditional group. The members were much more lively and excited to be participating in the study than were the traditional group members. The spiritual group members also interacted much more with each other than did the traditional group members who appeared to be more reserved. The spiritual group had



better attendance by its participants compared to the traditional group. The women in the spiritual group tended to mention spiritual issues on a much greater frequency than did the women in the other group.

## **Conclusion**

The results of the study indicate a general trend that the spiritual-based support group was associated with better mental well-being outcomes (reductions in depression, anger and anxiety) for African American breast cancer survivors. Findings give scientific recognition to the importance of spirituality as an activity which can be legitimately used to complement medical care. The study's findings are relevant to enhancing therapy and treatment outcomes for African American women with breast cancer as it sought to test the efficacy of a culturally tailored intervention for improving treatment related outcomes such as mental health and overall quality of life. In addition to the scientific outcomes, the study underscored the importance of relationships with various community organizations as well as with the Cancer Center staffs. Both in Detroit and in Newark, these relationships were necessary for the recruitment of participants in the study. We have also recognized that there were differences in the target population of African American breast cancer patients. In Detroit, the African American breast cancer patients served by the Karmanos Cancer Center were considerably more diverse socio-economically than in Newark. We could capture the diversity of African American women with breast cancer in Detroit where there were fewer cancer treatment facilities. In contrast, the Cancer Center in Newark serves a predominantly low income, uninsured population. The Greater Newark area also encompasses New York City with a wide choice of cancer treatment facilities for those

with health insurance. Given the different demographics, it was necessary to embark upon a variety of recruitment strategies. During the 18 months of actual program operation in Newark we were able to recruit only eight African American women who met the study criteria. However, with regard to recruitment of African American breast cancer patients, strategies are most successful when collaboration is obtained from the physicians and their staff.

Several revisions were made to the support group content including the addition of an Introduction session. In order to facilitate discussion from participants, the amount of material covered in the sessions was also reduced. Finally, it was important to provide transportation services for participants. While the findings suggest a general positive influence of the spiritual-based support group on overall quality of life for African American breast cancer survivors, they are limitations with regard to generalizability given the small sample size. Difficulties were also encountered in gathering data on treatment adherence given the restrictions on access to these data

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## **APPENDICES**

## Instruments

**SPIRITUAL- BASED SUPPORT GROUP INTERVENTION  
(DOD)**

**Pre- Test**

**STUDY ID NUMBER:** \_\_\_\_\_

**SSN (last 4 digits)**    \_\_\_\_ \_

**Revised – February 14, 2006**



**SECTION C: CONCURRENT STRESS INDEX (SMILKSTEIN & ZIMLICK, 1990)**

How would you rate the stress in your life now? "Stress" in this questionnaire refers to feelings of distress, tension or anxiety. Circle the number under the heading that seems to apply to you. All questions refer to events during the past 12 months.

For each question, circle only one number.

- 0=Never
- 1=Hardly Ever
- 2=Some of the Time
- 3=Almost Always
- 4=Always
- 5=Not Applicable (N/A)

		Never					N/A
1.	If you work outside the home, stress at work.	0	1	2	3	4	5
2.	If you go to school, stress at school.	0	1	2	3	4	5
3.	If during the past year you have moved, stress due to move.	0	1	2	3	4	5
4.	Stress due to concern about your health.		0	1	2	3	4 5
5.	Stress due to concern about sex.		0	1	2	3	4 5
6.	Stress with money or financial problems.	0	1	2	3	4	5
7.	Stress at home.		0	1	2	3	4 5
8.	If you are a parent, stress as a parent.	0	1	2	3	4	5

**SECTION C: CONCURRENT STRESS INDEX (Continued)**

0=Never  
 1=Hardly Ever  
 2=Some of the Time  
 3=Almost Always  
 4=Always  
 5=Not Applicable (N/A)

		Never					N/A	
9.	If you are married or living with a partner, stress with spouse or partner.	0	1	2	3	4	5	
10.	If during the past year you had a death in your family, stress due to death.	0	1	2	3	4	5	
11.	If during the past year you had a death of a friend, stress due to death of a friend.	0	1	2	3	4	5	
12.	If during the past year you had a divorce or separation, stress due to divorce or separation.	0	1	2	3	4	5	
13.	If you work, stress due to boss or supervisor.	0	1	2	3	4	5	
14.	If a member of your family is away from home, stress due to member being away.	0	1	2	3	4	5	
15.	If during the past year you have experienced lost of a pet, stress due to loss of pet.	0	1	2	3	4	5	
16.	If during the past year you were victim	0	1	2	3	4	5	

of a crime or you had a legal problem,  
stress due to crime or legal problem.

**SECTION C: CONCURRENT STRESS INDEX (Continued)**

0=Never  
1=Hardly Ever  
2=Some of the Time  
3=Almost Always  
4=Always  
5=Not Applicable (N/A)

		Never					N/A	
17.	If you have a close friend, stress due to relationship with friend.	0	1	2	3	4	5	
18.	If during the last year you have had an injury or illness problem, stress due to injury or illness.	0	1	2	3	4	5	
19.	If you are pregnant, stress due to pregnancy.	0	1	2	3	4	5	
20.	During the past year, if you have had a family member arrested, stress due to arrest of family member.	0	1	2	3	4	5	
21.	During the past year, a family member has been victim of a crime stress due to family member being victimized.	0	1	2	3	4	5	
22.	During the past year, a family member has been involved with drugs, stress due to family member's involvement with drugs.	0	1	2	3	4	5	
23.	During the past year, change in	0	1	2	3	4	5	

health of a family member, stress  
due to change in health of family  
member.

24. During the past year, change in living conditions, stress due to change in living conditions.      0      1      2      3      4      5

**SECTION D: SOCIO-DEMOGRAPHIC DATA (GARY, BROWN, ET AL, 1989)**

- D1. Where were you born?

\_\_\_\_\_  
City/state/country

- D2. When were you born?

\_\_\_\_/\_\_\_\_/\_\_\_\_  
month      day      year

- D3. Are you currently married, divorced, separated, widowed, or never married?

1. ☐ Married

2. ☐ Divorced

3. ☐ Separated

4. ☐ Widowed

5. ☐ Never married

- D4. How many grades or years of school have you finished?  
(Check the highest grade completed)

**Elementary**

01 02 03 04 05 06 07 08

**High School**

09 10 11 12

**College**

13 14 15 16

**Graduate**

17+

**SECTION D: SOCIO-DEMOGRAPHIC DATA (Continued)**

D5. Are you currently employed.....

1. ☐ Employed, how many hours per week \_\_\_\_\_

Has your illness affected your employment? Explain

\_\_\_\_\_  
\_\_\_\_\_

2. ☐ Medical Leave

3. ☐ Not employed

(a) If not employed, are you

1. unemployed, looking for work

2. retired

3. student

4. housewife/homemaker

5. disabled

6. other \_\_\_\_\_

(b) Are you not working because of your illness?

1. ☐ yes

2. ☐ no

D6. What do you consider your main occupation?

---

**Summary**

D1.Summary:

Total number of persons in household \_\_\_\_\_

Total number of adults 18 years + \_\_\_\_\_

Total number of children 0-17 years. \_\_\_\_\_

**SECTION D: SOCIO-DEMOGRAPHIC DATA (Continued)**

Below are listed questions about the people who live in the household with you. Please indicate the name, gender, age, and relationship to you.

**D2. Use the codes below to complete the household list:**

Relationships:

- |                        |                        |
|------------------------|------------------------|
| 1. HU= husband/partner | 10. FA= father         |
| 2. SO= son             | 11. MO= mother         |
| 3. DA= daughter        | 12. BR= brother        |
| 4. SI= sister          | 13. AT= aunt           |
| 5. UN= uncle           | 14. NC= niece          |
| 6. NP= nephew          | 15. CO= cousins        |
| 7. GC= grandchild      | 16. GF= grandfather    |
| 8. GM= grandmother     | 17. OR= other relative |
| 9. NR= non-relative    |                        |

Gender: 1) M= male 2) F= female

First name only	Relationship	Gender	Age
_____	_____	_____	_____
Household Member 1			
_____	_____	_____	_____
Household Member 2			
_____	_____	_____	_____
Household Member 3			
_____	_____	_____	_____
Household Member 4			
_____	_____	_____	_____
Household Member 5			

Household Member 6

Household Member 7

Household Member 8

**SECTION D: SOCIO-DEMOGRAPHIC DATA (Continued)**

Household Member 9

Household Member 10

Household Member 11

Household Member 12

D3. Who do you consider to be head of the household?

1. ☐ Self      2. ☐ Other, specify \_\_\_\_\_

D4. How many dependents do you have? \_\_\_\_\_  
Number

D5. Are there other people for whom you provide regular assistance or care?  
(Example: elderly parents, older relatives, children, grandchildren, adopted children)

(a) Yes, (give first name only)

Relationship

1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____

(b). ☐ No

D6. How many children have you given birth to?

[ ] \_\_\_\_\_  
number

[ ] NONE

D6a. How old were you when you gave birth to your first child?

Age \_\_\_\_\_

**SECTION E: CANCER BACKGROUND AND HISTORY (BROWN & SIMON, 1995)**

E1. Prior to the current diagnoses of breast cancer, have you previously been diagnosed with any type of cancer?

1. [ ] yes

If yes, what type?

\_\_\_\_\_ Breast  
\_\_\_\_\_ Lung  
\_\_\_\_\_ Colon  
\_\_\_\_\_ Ovarian  
\_\_\_\_\_ Other

2. [ ] no

E2. For current diagnoses, how did you discover that you had breast cancer?

1. [ ] breast lump through self-exam
2. [ ] routine clinical breast exam/doctor's visit
3. [ ] routine mammography
4. [ ] other \_\_\_\_\_

E3. For current diagnoses, when were you diagnosed with breast cancer?

Month \_\_\_\_\_ Year \_\_\_\_\_

E4. What was the stage at diagnosis? (Current diagnosis only)

1. [ ] I
2. [ ] II
3. [ ] III



4. ☐ IV
5. ☐ Don't Know

**SECTION E: CANCER BACKGROUND AND HISTORY (Continued)**

E5. How soon after you were diagnosed with breast cancer did you seek treatment?

1. ☐ Immediately -- 1-2 weeks
2. ☐ 3-6 weeks
3. ☐ More than 6 weeks

If more than 6 weeks – why did you delay seeking treatment?

---



---



---

E6. When did you first receive medical treatment for breast cancer?

Month \_\_\_\_\_ Year \_\_\_\_\_

E7. Have any of your blood relatives had breast cancer?

1. ☐ yes      2. ☐ no      Skip to Section E8.

- |                                      |        |       |               |
|--------------------------------------|--------|-------|---------------|
| a. <input type="checkbox"/> Sister 1 | 1. Yes | 2. No | 3. Don't know |
| b. <input type="checkbox"/> Sister 2 | 1. Yes | 2. No | 3. Don't know |
| c. <input type="checkbox"/> Sister 3 | 1. Yes | 2. No | 3. Don't know |
| d. <input type="checkbox"/> Sister 4 | 1. Yes | 2. No | 3. Don't know |
| e. <input type="checkbox"/> Mother   | 1. Yes | 2. No | 3. Don't know |

f. ☐ Paternal Aunt      1.Yes      2.No      3. Don't know

g. ☐ Maternal Aunt      1.Yes      2.No      3. Don't know

h. ☐ Paternal  
Grandmother      1.Yes      2.No      3. Don't know

i. ☐ Maternal  
Grandmother      1.Yes      2.No      3. Don't know

**SECTION E:      CANCER BACKGROUND AND HISTORY (Continued)**

j. ☐ Daughter      1.Yes      2.No      3. Don't know

k. ☐ Daughter      1.Yes      2.No      3. Don't know

l. ☐ Other      1.Yes      2.No      3. Don't know

E8. In terms of your overall health, during the past 12 months, have you had any of the following: **(CHECK ALL THAT APPLY)**

1. ☐ Poor vision
2. ☐ Poor hearing
3. ☐ Respiratory infection
4. ☐ Convalescence from surgery-other than related to breast cancer
5. ☐ Injury/ deformity
6. ☐ Arthritis or Rheumatism
7. ☐ Heart disease
8. ☐ High blood pressure (hypertension)
9. ☐ Stroke
10. ☐ Diabetes
11. ☐ Chronic lung disease (emphysema, asthma)
12. ☐ Ulcers
13. ☐ Liver problem
14. ☐ Kidney problem
15. ☐ Nervous condition
16. ☐ Allergies
17. ☐ Sickle cell anemia
18. ☐ HIV/AIDS

19. [ ] Other (specify) \_\_\_\_\_
20. [ ] None

## **SECTION F: SPIRITUAL WELL BEING (ELLISON & PALOUTZIAN, 1982)**

For each of the following statements circle the choice that best indicates the extent of your agreement or disagreement as it describes your personal experience.

6=Strongly Agree  
5=Moderately Agree  
4=Agree

3=Disagree  
2=Moderately Disagree  
1=Strongly Disagree

- |  |   |   |   |   |   |   |
|--|---|---|---|---|---|---|
| 1. I don't find much satisfaction in prayer with God.                          | 6 | 5 | 4 | 3 | 2 | 1 |
| 2. I don't know who I am, where I came from or where I am going.               | 6 | 5 | 4 | 3 | 2 | 1 |
| 3. I believe that God loves me and cares about me.                             | 6 | 5 | 4 | 3 | 2 | 1 |
| 4. I feel that life is a positive experience.                                  | 6 | 5 | 4 | 3 | 2 | 1 |
| 5. I believe that God is impersonal and not interested in my daily situations. | 6 | 5 | 4 | 3 | 2 | 1 |
| 6. I feel unsettled about my future.   | 6 | 5 | 4 | 3 | 2 | 1 |
| 7. I have a personally meaningful relationship with God.                       | 6 | 5 | 4 | 3 | 2 | 1 |
| 8. I feel very fulfilled and satisfied   |   |   |   |   |   |   |

with life.	6	5	4	3	2	1
9. I don't get much personal strength and support from my God.	6	5	4	3	2	1
10. I feel a sense of well-being about the direction my life is headed in.	6	5	4	3	2	1
11. I believe that God is concerned about my problems.	6	5	4	3	2	1

**SECTION F: SPIRITUAL WELL BEING (Continued)**

6=Strongly Agree  
5=Moderately Agree  
4=Agree

3=Disagree  
2=Moderately Disagree  
1=Strongly Disagree

12. I don't enjoy much about life.	6	5	4	3	2	1
13. I don't have a personally satisfying relationship with God.	6	5	4	3	2	1
14. I feel good about my future.	6	5	4	3	2	1
15. My relationship with God helps me not feel lonely.	6	5	4	3	2	1
16. I feel that life is full of conflict and unhappiness.	6	5	4	3	2	1
17. I feel most fulfilled when I'm in close communion with God.	6	5	4	3	2	1
18. Life doesn't have much meaning.	6	5	4	3	2	1
19. My relationship with God contributes to my sense of well-being.	6	5	4	3	2	1
20. I believe there is some real purpose for my life.	6	5	4	3	2	1

**SECTION G. HELP SEEKING AND DECISION MAKING (GARY, BROWN, ET. AL, 1989)**

Questions about the process you used to seek and decide upon treatment.

G1. After you were informed of the diagnosis of breast cancer, with whom did you **first confide and share** this information?

1.	First person (first name only)	Relationship
	_____	_____

**SECTION G. HELP SEEKING AND DECISION MAKING (Continued)**

G2. With what other persons did you confide and share this information?

	Name (first name only)	Relationship
2.	_____	_____
3.	_____	_____
4.	_____	_____

G3. At any point were you ever reluctant to tell others (family, pastor, friends, co-workers, etc.) about the diagnosis of breast cancer?

1. ☐ Yes, If yes, explain

1. ☐ afraid

2. ☐ ashamed

3. ☐ other

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

☐ No

G4. When you were informed by the physician that you had breast cancer, to whom did you go to **first for advice and consultation** regarding treatment?

1. ☐ Husband/partner

2. ☐ Family member, specify \_\_\_\_\_
3. ☐ Friend
4. ☐ Physician
5. ☐ Other medical professional
6. ☐ Member of the Clergy
7. ☐ Other, specify \_\_\_\_\_

### **SECTION G. HELP SEEKING AND DECISION MAKING (Continued)**

G5. To whom did you go to second?

1. ☐ Husband/partner
2. ☐ Family member, specify \_\_\_\_\_
3. ☐ Friend
4. ☐ Physician
5. ☐ Other medical professional
6. ☐ Member of the Clergy
7. ☐ Other, specify \_\_\_\_\_

G6. To whom did you go to third?

1. ☐ Husband/partner
2. ☐ Family member, specify \_\_\_\_\_
3. ☐ Friend
4. ☐ Physician
5. ☐ Other medical professional
6. ☐ Member of the Clergy
7. ☐ Other, specify \_\_\_\_\_

G7. Have you sought any complimentary or alternative treatments (i.e. nutritional treatment, faith healing or herbal remedies) for breast cancer?

1. ☐ Yes, Please describe

---

---

2. [ ] No

G8. Who has most influenced your decisions about treatment (e.g., family, friends, doctor, other medical professional, etc.)?

List in rank order.

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

**SECTION H: MENTAL WELL BEING (CES-D (RADLOFF, 1977))**

I will read a list of ways you may have felt or behaved. Please indicate how often you have felt or behaved this way **during the past week:**  
rarely or none of the time; some or little of the time; occasionally or a moderate amount of time; or most or all of the time.

RARELY OR NONE OF THE TIME (LESS THAN 1 DAY) 0

SOME OR LITTLE OF THE TIME (1-2 DAYS) 1

OCCASIONALLY OR A MODERATE AMOUNT OF TIME 2  
(3-4 DAYS)

MOST OR ALL OF THE TIME (5-7 DAYS) 3

a. I was bothered by things that usually don't bother me. 0 1 2 3

b. I did not feel like eating; my appetite was poor. 0 1 2 3

c. I felt that I could not shake off the blues even with help from family and friends. 0 1 2 3

d. I felt that I was just as good as other people. 0 1 2 3

e. I had trouble keeping my mind on what I was doing. 0 1 2 3

f. I felt depressed.	0	1	2	3
g. I felt that everything I did was an effort.	0	1	2	3
h. I felt hopeful about my future.	0	1	2	3
i. I thought my life had been a failure.	0	1	2	3
j. I felt fearful.	0	1	2	3
k. My sleep was restless.	0	1	2	3
l. I was happy.	0	1	2	3
m. I talked less than usual.	0	1	2	3

**SECTION H: MENTAL WELL BEING (Continued)**

RARELY OR NONE OF THE TIME (LESS THAN 1 DAY) 0

SOME OR LITTLE OF THE TIME (1-2 DAYS) 1

OCCASIONALLY OR A MODERATE AMOUNT OF TIME (3-4 DAYS) 2

MOST OR ALL OF THE TIME (5-7 DAYS) 3

n. I felt lonely.	0	1	2	3
o. People were unfriendly.	0	1	2	3
p. I enjoyed life.	0	1	2	3
q. I had crying spells.	0	1	2	3
r. I felt sad.	0	1	2	3
s. I felt that people dislike me.	0	1	2	3
t. I could not get "going".	0	1	2	3



## **SECTION I: ACCESSIBILITY**

11. What is the TOTAL annual income of ALL the persons living in your household, that is considering all sources such as jobs, Social Security, retirement income, salaries, wages, unemployment compensation, profits, interest, and so on?

1. ☐ Less than \$5,000
2. ☐ \$ 5,000- \$9,999
3. ☐ \$10,000- \$14,999
4. ☐ \$15,000- \$19,999
5. ☐ \$20,000- \$24,999
6. ☐ \$25,000- \$29,999
7. ☐ \$30,000- \$39,999
8. ☐ \$40,000- \$49,999
9. ☐ \$50,000- \$59,999
10. ☐ \$60,000- \$69,999
11. ☐ \$70,000- \$79,999
12. ☐ \$80,000- \$89,999
13. ☐ \$90,000- \$99,999
14. ☐ \$100,000 or more

12. What is the YOUR personal annual income, that is considering all sources such as jobs, Social Security, retirement income, salaries, wages, unemployment compensation, profits, interests, etc.

1. ☐ Less than \$5,000
2. ☐ \$ 5,000- \$9,999
3. ☐ \$10,000- \$14,999
4. ☐ \$15,000- \$19,999
5. ☐ \$20,000- \$24,999
6. ☐ \$25,000- \$29,999
7. ☐ \$30,000- \$39,999
8. ☐ \$40,000- \$49,999
9. ☐ \$50,000- \$59,999
10. ☐ \$60,000- \$69,999
11. ☐ \$70,000- \$79,999
12. ☐ \$80,000- \$89,999
13. ☐ \$90,000- \$99,999
14. ☐ \$100,000 or more

**SECTION I: ACCESSIBILITY (Continued)**

I3. Do you have access to a car or have transportation when you need to visit the doctor for breast cancer treatment?

1. ☐ Yes

2. ☐ No If no, is this an obstacle to your receiving treatment or routine health care? \_\_\_\_\_

I4. Do you have health insurance coverage for yourself?

1. ☐ Yes

If yes, what type \_\_\_\_\_  
Blue Cross/ Blue Shield, Health Plus, DMC, Other

2. ☐ No

I5. Are you covered by MEDICAID? (NOT Medicare)

1. ☐ Yes

2. ☐ No

3. ☐ Don't Know

I6. Does your health insurance cover all the costs of your medical treatment for breast cancer?

1. ☐ Yes, all costs

2. ☐ Yes, partial costs

3. ☐ No

**SECTION J: EXTERNAL RESOURCES AND SOCIAL SUPPORT (GARY & BROWN, ET. AT, 1989)**

J1a. How many total family members who you see or talk with regularly live nearby, that is less than 50 miles away?

\_\_\_\_\_

J1b. How often do people in your family – including children, grandparents, uncles, in-laws, and so on- help you out?

- ☐ Very Often
- ☐ Fairly Often
- ☐ Not too often
- ☐ Never (If Never, Skip to J5)

**Only If Relatives Help**

J2. How much help are your family members to you?

- ☐ A great deal of help
- ☐ A lot of help
- ☐ Only a little help

J3. In what ways are your family members most helpful to you? Please specify?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

J4. How satisfied are you with the help you receive from your family members?

- ☐ Very satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied or dissatisfied
- ☐ Somewhat dissatisfied

☐ Very dissatisfied

**SECTION J: EXTERNAL RESOURCES AND SOCIAL SUPPORT (Continued)**

J5. How many total friends who you see or talk with regularly live nearby, that is less than 50 miles away?

\_\_\_\_\_

J6. How often do your friends help out?

☐ Very Often

☐ Fairly Often

☐ Not too often

☐ Never

(If Never, Skip to J10)

**Only If Friends Help**

J7. How much help are your friends to you?

☐ A great deal of help

☐ A lot of help

☐ Only a little help

J8. In what ways are your friends most helpful to you? Please specify?

\_\_\_\_\_  
\_\_\_\_\_

J9. How satisfied are you with the help you receive from your friends?

☐ Very satisfied

☐ Somewhat satisfied

☐ Neither satisfied or dissatisfied

☐ Somewhat dissatisfied

☐ Very dissatisfied

**SECTION J: EXTERNAL RESOURCES AND SOCIAL SUPPORT (Continued)**

J10. Is there anyone to whom you can really open up about your most private feelings without having to hold back?

1. ☐ Yes, who is this? \_\_\_\_\_  
(relationship) \_\_\_\_\_

2. ☐ No

J11. Has having breast cancer in any way affected your family life or the relationships among family members?

a. ☐ Yes, in what ways?

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

b. ☐ No

J12. Since being diagnosed with breast cancer, have you seen or sought counseling with a social worker, psychologist, psychiatrist or any other mental health professional?

☐ Yes, explained \_\_\_\_\_

☐ No

J13. Are you currently seeing a social worker, psychologist, psychiatrist or any other mental health professional?

☐ Yes

☐ No

J14. Do you belong to a breast cancer support group?

1. ☐ Yes
  - a. How long have you been a member? \_\_\_\_\_  
Months
  - b. How helpful has this group been to you?
    3. ☐ A great deal of help
    2. ☐ A lot of help
    1. ☐ Only a little help
2. ☐ No
  - a. If no, would you be interested in finding out about support groups in our area?
   
  
☐ Yes  
☐ No

## **SECTION K: STRESSES AND PROBLEM (HOLMES & RAHE, 1975)**

This section deals with stresses and problems you may have had.

K1. Within the PAST 12 MONTHS, have you experienced:

**Record by placing an X in the right column for the events that the Respondent has experienced.**

	During the past 12 months
(1) an illness or injury which:	
(a) kept you in bed a week or more, or took you to the hospital?	_____
(b) an injury which was less serious than I just described?	_____
(2) a major change in eating habits?	_____
(3) a major change in sleeping habits?	_____
(4) a change in your usual type and/or amount of recreation?	_____

**SECTION K: STRESSES AND PROBLEM (Continued)**

During the past  
12 months

(5) major dental work? \_\_\_\_\_

**Note for respondents who are not working (Skip to 10)**

Have you:

(6) changed to a new type of work? \_\_\_\_\_

(7) changed your work hours or conditions? \_\_\_\_\_

(8) had a change in your responsibilities  
at work: \_\_\_\_\_

(a) more responsibilities? \_\_\_\_\_

(b) less responsibilities? \_\_\_\_\_

(c) promotion? \_\_\_\_\_

(d) demotion? \_\_\_\_\_

(e) transfer? \_\_\_\_\_

(9) experienced troubles at work: \_\_\_\_\_

(a) with your boss? \_\_\_\_\_

(b) with co-workers? \_\_\_\_\_

(c) with persons under your supervision? \_\_\_\_\_

(d) other work troubles? \_\_\_\_\_

(10) experienced a major business  
readjustment? \_\_\_\_\_

(11) retired? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

During the past  
12 months

- (12) experienced being:
- (a) fired from work? \_\_\_\_\_
  - (b) laid off from work? \_\_\_\_\_
- (13) taken courses by mail or studied  
at home to help you in your work? \_\_\_\_\_
- (14) a change in residence:
- (a) a move within the same town or city? \_\_\_\_\_
  - (b) a move to a different town, city or state? \_\_\_\_\_
- (15) a change in family "get-togethers" ? \_\_\_\_\_
- (16) a major change in the health or behavior  
of a family member (illness, accidents,  
drug or disciplinary problems, etc.)? \_\_\_\_\_
- (17) major change in your living conditions  
(home improvements or a decline in your  
home or neighborhood)? \_\_\_\_\_
- (18) the death of a spouse? \_\_\_\_\_
- (19) the death of a:
- (a) child? \_\_\_\_\_
  - (b) brother or sister? \_\_\_\_\_
  - (c) parent? \_\_\_\_\_
  - (c) other close family member? \_\_\_\_\_



(20) the death of a close friend? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

During the past  
12 months

(21) change in the marital status of your parents:

(a) divorce? \_\_\_\_\_

(b) remarriage? \_\_\_\_\_

(c) legally separated? \_\_\_\_\_

**NOTE: (RESPONDENTS WHO ARE MARRIED GO TO  
QUESTIONS 22 TO 28.  
FOR PERSONS NEVER MARRIED, GO TO 29)**

(22) marriage? \_\_\_\_\_

(23) a change in arguments with your spouse? \_\_\_\_\_

(24) in- law problems? \_\_\_\_\_

(25) a separation from spouse:

(a) due to work? \_\_\_\_\_

(b) due to marital problems? \_\_\_\_\_

(26) a reconciliation with spouse? \_\_\_\_\_

(27) a divorce? \_\_\_\_\_

(28) your spouse beginning or ceasing work  
outside the home? \_\_\_\_\_

(29) a gain of a new family member:

(a) birth of a child? \_\_\_\_\_

(b) adoption of a child? \_\_\_\_\_

(c) a relative moving in with you? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

During the past  
12 months

(30) you becoming pregnant? \_\_\_\_\_

(31) you having a miscarriage or abortion? \_\_\_\_\_

NOTE:

**(QUESTIONS 32 AND 33 CONCERN CHILDREN. FOR PERSONS WHO DO NOT HAVE CHILDREN, GO TO 34)**

(32) a child leaving home:

(a) due to marriage? \_\_\_\_\_

(b) to attend college? \_\_\_\_\_

(c) for other reasons? \_\_\_\_\_

(33) birth of a grandchild? \_\_\_\_\_

(34) a major personal achievement? \_\_\_\_\_

(35) a change in your personal habits  
(your dress, friends, lifestyles, etc.)? \_\_\_\_\_

(36) sexual difficulties? \_\_\_\_\_

(37) beginning or ceasing school or college? \_\_\_\_\_

(38) a change of school or college? \_\_\_\_\_

(39) a vacation? \_\_\_\_\_

(40) a change in your religious beliefs? \_\_\_\_\_

- (41) a change in your social activities \_\_\_\_\_  
(clubs, movies, visiting)?

**SECTION K: STRESSES AND PROBLEM (Continued)**

- During the past  
12 months
- (42) a minor violation of the law? \_\_\_\_\_
- (43) legal troubles resulting in your  
being held in jail? \_\_\_\_\_
- (44) a change in your political beliefs? \_\_\_\_\_
- (45) a new, close, personal relationship? \_\_\_\_\_
- (46) an engagement to marry? \_\_\_\_\_
- (47) a "falling out" of a close personal  
relationship? \_\_\_\_\_
- (48) girlfriend (or boyfriend) problems? \_\_\_\_\_
- (49) a loss or damage of personal property? \_\_\_\_\_
- (50) an accident? \_\_\_\_\_
- (51) a major decision regarding your  
immediate future? \_\_\_\_\_

Have you:

- (52) taken on a moderate purchase, such as  
a T.V., car, freezer, etc.) \_\_\_\_\_
- (53) taken on a major purchase or a  
mortgage loan, such as a home,  
business, property, etc.? \_\_\_\_\_

(54) experienced a foreclosure on a \_\_\_\_\_  
mortgage or loan?

**SECTION K: STRESSES AND PROBLEM (Continued)**

During the past  
12 months

(55) experienced a major change in finances:

(a) increased income? \_\_\_\_\_

(b) decreased income? \_\_\_\_\_

(c) credit rating difficulties? \_\_\_\_\_

**SECTION L: RELIGIOUS PRACTICES & BEHAVIOR**

L1. What is your religious denominational preference? (Check one)

1. ☐ None

2. ☐ Protestant, (specify) \_\_\_\_\_

3. ☐ Jewish

4. ☐ Catholic

5. ☐ Muslim (Islamic)

6. ☐ Other, (specify) \_\_\_\_\_

## **SECTION L: RELIGIOUS PRACTICES & BEHAVIOR**

L2. Using the expressions- very often, often, sometimes, almost never, and never, please describe ways in which you are involved in religion.

	1- Very often			4- Almost never	
	2- Often			5- Never	
	3- Sometimes				
	Very often			Never	
1. I attend religious crusades, revival meetings or missions.	1	2	3	4	5
2. I attend religious services.	1	2	3	4	5
3. I listen to religious services on the Radio, TV or internet.	1	2	3	4	5
4. I sometimes pray, either privately or with family.	1	2	3	4	5
5. I listen to religious music.	1	2	3	4	5
6. Ideas I have learned from religion some times help me understand my own life.	1	2	3	4	5
7. I contribute money to church ( or other religious institutions).	1	2	3	4	5
8. I regularly take part in various religious organizations.	1	2	3	4	5
9. I feel that the church or religion helps me in getting ahead in life.	1	2	3	4	5

10. The religious beliefs I learned  
when I was young still help me.                      1            2            3            4            5

**SECTION L:    RELIGIOUS PRACTICES & BEHAVIOR (Continued)**

L3.    How religious would you say you are?

1. ☐ very religious
2. ☐ somewhat religious
3. ☐ not very religious
4. ☐ not at all religious
5. ☐ don't know
6. ☐ refused

L4.    Has your religious involvement changed since your diagnosis of  
breast cancer?

1. ☐ yes, how?

☐ increased? Explain \_\_\_\_\_

☐ decreased? Explain \_\_\_\_\_

2. ☐ no, remained the same

L5.    To what extent has your religious involvement helped you deal with  
breast cancer?

☐ A great deal

☐ Somewhat

☐ No help

L6.    In the past year, have you gone to a minister, or elder for guidance  
when faced with a problem?

1. ☐ Yes

2. ☐ No    (SKIP TO SECTION L7)

If yes, what kind of problem(s) have you discussed with these persons?    (MARK  
ALL THAT APPLY)

- |   |  |
|---|--|
| 1. <input type="checkbox"/> Breast Cancer   | 2. <input type="checkbox"/> Money                    |
| 3. <input type="checkbox"/> Job             | 4. <input type="checkbox"/> Accident                 |
| 5. <input type="checkbox"/> Worry (anxiety) | 6. <input type="checkbox"/> Family                   |
| 7. <input type="checkbox"/> Spiritual       | 8. <input type="checkbox"/> Marital                  |
| 9. <input type="checkbox"/> Divorce         | 10. <input type="checkbox"/> Feeling low, depression |

11. ☐ Other Health Issue (Specify) \_\_\_\_\_

12. ☐ Other Problem, (Specify) \_\_\_\_\_

**SECTION L: RELIGIOUS PRACTICES & BEHAVIOR (Continued)**

L7. In dealing with your illness, how much or how frequently have you done or used the following?

- 1= Not at all  
 2= Somewhat  
 3= Quite a bit  
 4= A great deal

- \_\_\_\_\_ A. Called a prayer partner
- \_\_\_\_\_ B. Performed religious rituals such as saying the rosary
- \_\_\_\_\_ C. Provide testimony about your illness
- \_\_\_\_\_ D. Asked someone to pray for you
- \_\_\_\_\_ E. Meditated
- \_\_\_\_\_ F. Prayed by yourself
- \_\_\_\_\_ G. Prayed with others
- \_\_\_\_\_ H. Telephoned prayer line
- \_\_\_\_\_ I. Read or recited scriptures or inspirational verses
- \_\_\_\_\_ J. Listened to spirituals or other music, e.g. radio, Cds.
- \_\_\_\_\_ K. Watched religious programs on TV
- \_\_\_\_\_ L. Attended religious services

- ☐ M. Attended religious retreat
- ☐ N. Participated in testifying, witnessing, giving praise
- ☐ O. Participated in a support group within the church
- ☐ P. Participated in family activities

L7. In dealing with your illness, how much or how frequently have you done or used the following?

- 1= Not at all
- 2= Somewhat
- 3= Quite a bit
- 4= A great deal

- ☐ Q. Participated in Bible study classes/ groups
- ☐ R. Attended revivals, prayer meetings
- ☐ S. Read inspirational books
- ☐ T. Talked to God, holy spirit, higher power
- ☐ U. Kept a diary or journal
- ☐ V. Received counseling from member of clergy

## **SECTION M: FACT-B (VERSION 3) CELLA ET AL., 1993**

### **PHYSICAL WELL-BEING**

Below is a list of statements that other people with your illness have said are important. By circling one number per line, please indicate how true each statement has been for you during the past 7 days.

- 0= Not at all
- 1= A little bit
- 2= Somewhat
- 3= Quite a bit



4= Very much

	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I have a lack of energy .....	0	1	2	3	4
2. I have nausea.....	0	1	2	3	4

**SECTION M: FACT-B (VERSION 3) (Continued)**

	Not at all	A little bit	Some- what	Quite a bit	Very much
3. Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
4. I have pain.....	0	1	2	3	4
5. I am bothered by side effects of treatment...	0	1	2	3	4
6. I feel sick.....	0	1	2	3	4
7. I am forced to spend time in bed .....	0	1	2	3	4

**SOCIAL/FAMILY WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much	
8. I feel distant from my friends.....		0	1	2	3	4
9. I get emotional support from my family....	0	1	2	3	4	
10. I get support from my friends and neighbors	0	1	2	3	4	
11. My family has accepted my illness.....	0	1	2	3	4	
12. Family communication about my illness... is poor	0	1	2	3	4	
13. I feel close to my partner (or the person who is my main support).....	0	1	2	3	4	
14. Have you been sexually active during the						

past year?.....[ ] No  
[ ] Yes

If yes: I am satisfied with my sex life..... 0 1 2 3 4

## **SECTION M: FACT-B (VERSION 3) (Continued)**

### **FUNCTIONAL WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much
15. I am able to work (include work in home)..	0	1	2	3	4
16. My work (include work in home) is fulfilling.....	0	1	2	3	4
17. I am able to enjoy life.....	0	1	2	3	4
18. I have accepted my illness.....	0	1	2	3	4
19. I am sleeping well.....	0	1	2	3	4
20. I am enjoying the things I usually do for fun.....	0	1	2	3	4
21. I am content with the quality of my life right now.....	0	1	2	3	4

### **EMOTIONAL WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much
22. I feel sad.....	0	1	2	3	4
23. I am proud of how I'm coping with my illness.....	0	1	2	3	4
24. I am losing hope in the fight against my					

illness.....	0	1	2	3	4
25. I feel nervous.....	0	1	2	3	4
26. I worry about dying.....	0	1	2	3	4
27. I worry that my condition will get worse ...	0	1	2	3	4

### **SECTION M: FACT-B (VERSION 3) (Continued)**

#### **ADDITIONAL CONCERN**

	Not at all	A little bit	Some- what	Quite a bit	Very much
28. I have been short of breath .....	0	1	2	3	4
29. I am self-conscious about the way I dress....	0	1	2	3	4
30. My arms are swollen or tender.....	0	1	2	3	4
31. I feel sexually attractive.....	0	1	2	3	4
32. I have been bothered by hair loss.....	0	1	2	3	4
33. I worry about the risk of cancer in other family members.....	0	1	2	3	4

### **SECTION N: HEALTH PROMOTION LIFESTYLE PROFILE (WALKER, SECHRIST & PENDER, 1987)**

N1. How frequently do you perform the following activities?

1=Never

2=Sometimes

3=Often

4=Routinely

	Never			Routinely
1. Check for cholesterol level	1	2	3	4

2.	Report symptoms to M.D.	1	2	3	4
3.	Read books about health	1	2	3	4
4.	Question M.D. / second opinion	1	2	3	4
5.	Discuss health concerns	1	2	3	4
6.	Check blood pressure	1	2	3	4
7.	Seek information	1	2	3	4

**SECTION N: HEALTH PROMOTION LIFESTYLE PROFILE (Continued)**

N1. How frequently do you perform the following activities?

1=Never

2=Sometimes

3=Often

4=Routinely

		Never			Routinely
8.	Attend environmental programs	1	2	3	4
9.	Observe body for changes	1	2	3	4
10.	Attend health care programs	1	2	3	4
11.	Do stretching exercise	1	2	3	4
12.	Vigorous exercise 3 times per week	1	2	3	4
13.	Supervised exercise programs	1	2	3	4
14.	Recreational activities	1	2	3	4
15.	Check pulse rate	1	2	3	4
16.	Eat breakfast	1	2	3	4
17.	Eat three meals daily	1	2	3	4

18.	Use no preservatives	1	2	3	4
19.	Read labels	1	2	3	4
20.	Eat roughage/ fiber	1	2	3	4
21.	Eat basic 4 foods groups	1	2	3	4
22.	Discuss concerns/ problems	1	2	3	4
23.	Spend daily relaxation time	1	2	3	4
24.	Are aware of stress sources	1	2	3	4
25.	Engage in meditation/relaxation	1	2	3	4
26.	Relax muscles before sleep	1	2	3	4
27.	Have pleasant bedtime thoughts	1	2	3	4
28.	Express feelings	1	2	3	4
29.	Use stress controls methods	1	2	3	4

N2. Do you currently smoke cigarettes?

Yes \_\_\_\_\_ On average, about how cigarettes on a typical day do you currently smoke? \_\_\_\_\_

No \_\_\_\_\_

N3. Do you drink alcohol (wine, beer, liquor)

Yes \_\_\_\_\_ If yes, how often do you have a drink of alcohol?

Daily or almost daily  
Weekly  
Monthly  
Less than once a month

No \_\_\_\_\_ Rarely

**SECTION O: PATIENT COMPLIANCE (RHEINER, 1994)**

Please complete the following sentences with the choices listed below:

1= Always

2= Usually

3= Seldom

4=Never

1. Follow the recommendations of your doctor(s). 1      2      3      4

For “seldom or never” PROBE for barriers

---

---

2. Use drugs other than those prescribed for me      1      2      3      4  
during this period in my life.

For “always or usually” PROBE for barriers

---

---

3. Objected to doing those things that are required 1      2      3      4  
in your treatment program

For “always or usually” PROBE for barriers

---

---

4. Attempted to avoid doing those things that were 1      2      3      4  
required by your treatment program

For “always or usually” PROBE for barriers

---

---

5. Missed appointments scheduled with the doctor 1      2      3      4

For “always or usually” PROBE for barriers

---

---

**SECTION O: PATIENT COMPLIANCE (Continued)**

6. Understand your treatment program is important but fail to follow it. 1 2 3 4

For “always or usually” PROBE for barriers

---

---

7. Believe that your treatment program will increase your prospects for recovery 1 2 3 4

For “seldom or never” PROBE for barriers

---

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This concludes our questionnaire. Thank you for willingness to participate and to share this information with us.



*Please complete and return this survey to The Institute for the Elimination of Health Disparities, University of Medicine and Dentistry of New Jersey– 65 Bergen Street – Suite 1346 – Newark, NJ 07107. Thank you for your involvement.*

## **SECTION A: PROFILE OF MOOD STATES**

Below is a list of words that describe feelings people have. Please read each one carefully. Circle the answer which best describes **How you have been feeling during the past week including today?**

O = Not at all    1 = A little bit    2 = Moderately    3 = Quite a bit    4= Extremely

		<u>Not at all</u>			<u>Extremely</u>	
		0	1	2	3	4
1.	Friendly	0	1	2	3	4
2.	Tense	0	1	2	3	4
3.	Angry	0	1	2	3	4
4.	Worn Out	0	1	2	3	4
5.	Unhappy	0	1	2	3	4
6.	Clear-headed	0	1	2	3	4
7.	Lively	0	1	2	3	4
8.	Confused	0	1	2	3	4
9.	Sorry for things done	0	1	2	3	4
10.	Shaky	0	1	2	3	4
11.	Listless	0	1	2	3	4
12.	Peeved	0	1	2	3	4
13.	Considerate	0	1	2	3	4
14.	Sad	0	1	2	3	4

## **SECTION A: PROFILE OF MOOD STATES (Continued)**

### **How you have been feeling during the past week including today?**

O = Not at all    1 = A little bit    2 = Moderately    3 = Quite a bit    4 = Extremely

	<u>Not at all</u>				<u>Extremely</u>
15. Active	0	1	2	3	4
16. On edge	0	1	2	3	4
17. Grouchy	0	1	2	3	4
18. Blue	0	1	2	3	4
19. Energetic	0	1	2	3	4
20. Panicky	0	1	2	3	4
21. Hopeless	0	1	2	3	4
22. Relaxed	0	1	2	3	4
23. Unworthy	0	1	2	3	4
24. Spiteful	0	1	2	3	4
25. Sympathetic	0	1	2	3	4
26. Uneasy	0	1	2	3	4
27. Restless	0	1	2	3	4
28. Unable to concentrate	0	1	2	3	4
29. Fatigued	0	1	2	3	4
30. Helpful	0	1	2	3	4

## **SECTION A: PROFILE OF MOOD STATES (Continued)**

### **How you have been feeling during the past week including today?**

O = Not at all    1 = A little bit    2 = Moderately    3 = Quite a bit    4 = Extremely

	<u>Not at all</u>				<u>Extremely</u>
31. Annoyed	0	1	2	3	4
32. Discouraged	0	1	2	3	4
33. Resentful	0	1	2	3	4
34. Nervous	0	1	2	3	4
35. Lonely	0	1	2	3	4
36. Miserable	0	1	2	3	4
37. Muddled	0	1	2	3	4
38. Cheerful	0	1	2	3	4
39. Bitter	0	1	2	3	4
40. Exhausted	0	1	2	3	4
41. Anxious	0	1	2	3	4
42. Ready to fight	0	1	2	3	4
43. Good natured	0	1	2	3	4
44. Gloomy	0	1	2	3	4
45. Desperate	0	1	2	3	4



**SECTION A: PROFILE OF MOOD STATES (Continued)**

**How you have been feeling during the past week including today?**

O = Not at all    1 =A little bit    2 = Moderately    3 = Quite a bit    4= Extremely

	Not at all				Extremely
46. Sluggish	0	1	2	3	4
47. Rebellious	0	1	2	3	4
48. Helpless	0	1	2	3	4
49. Weary	0	1	2	3	4
50. Bewildered	0	1	2	3	4
51. Alert	0	1	2	3	4
52. Deceived	0	1	2	3	4
53. Furious	0	1	2	3	4
54. Efficient	0	1	2	3	4
55. Trusting	0	1	2	3	4
56. Full of pep	0	1	2	3	4
57. Bad-tempered	0	1	2	3	4
58. Worthless	0	1	2	3	4
59. Forgetful	0	1	2	3	4
60. Carefree	0	1	2	3	4
61. Terrified	0	1	2	3	4
62. Guilty	0	1	2	3	4

**SECTION A: PROFILE OF MOOD STATES (Continued)**

**How you have been feeling during the past week including today?**

O = Not at all    1 = A little bit    2 = Moderately    3 = Quite a bit    4 = Extremely

		Not at all				Extremely
63.	Vigorous	0	1	2	3	4
64.	Uncertain about things	0	1	2	3	4
65.	Bushed	0	1	2	3	4

**SECTION B: DEALING WITH ILLNESS (FAWZY, ET AL., 1990)**

The following is a list of things people do to deal with problems in their lives. Which of these things have you used recently to help deal with your illness?

1= Never          2= Rarely          3= Sometimes          4= Often          5= Always

		Never				Always
1.	Thought about my illness but tried not to let it overly upset or overwhelm me.	1	2	3	4	5
2.	Tried to keep others from knowing how I was feeling.	1	2	3	4	5
3.	Prayed hard for a good ending to the situation.	1	2	3	4	5
4.	Thought about it one day at a time.	1	2	3	4	5
5.	Went out more socially.	1	2	3	4	5

**SECTION B: DEALING WITH ILLNESS (Continued)**

1= Never		2= Rarely		3= Sometimes		4= Often		5= Always	
				Never				Always	
6.	Accepted the reality of my diagnosis but did not automatically accept a poor outlook.	1	2	3	4	5			
7.	Talked to people just to be able to talk about it.	1	2	3	4	5			
8.	Thought about the positive changes in me since the illness.	1	2	3	4	5			
9.	Went to a friend, or professional for advice on how to change things in the situation.	1	2	3	4	5			
10.	Avoided being with people.	1	2	3	4	5			
11.	Tried to get someone, like a doctor, to do something about it.	1	2	3	4	5			
12.	Took more vitamins and ate healthy foods.	1	2	3	4	5			
13.	Simply refused to even think about the situation as I just couldn't face it.	1	2	3	4	5			
14.	Went to a friend or a professional to help me feel better.	1	2	3	4	5			
15.	Formed a plan of action in my mind.	1	2	3	4	5			
16.	Thought more the meaning of life.	1	2	3	4	5			
17.	Trusted my belief in God.	1	2	3	4	5			

## **SECTION B: DEALING WITH ILLNESS (Continued)**

	1= Never	2= Rarely	3= Sometimes	4= Often	5= Always
			Never		Always
18.	Talked with others in the same situation.			1 2 3	4 5
19.	Prepared for the worst.			1 2 3	4 5
20.	Turned to work or other activities to keep my mind off things.			1 2 3	4 5
21.	Enjoyed everyday things more than I used to.			1 2 3	4 5
22.	Developed myself as a person.			1 2 3	4 5
23.	Exercised more than usual.			1 2 3	4 5
24.	Drank more alcohol than usual.			1 2 3	4 5
25.	Ate more than usual.			1 2 3	4 5
26.	Smoked more than usual.			1 2 3	4 5
27.	Took prescription/ illegal drugs more than usual.			1 2 3	4 5
28.	Slept more than usual.			1 2 3	4 5
29.	Worked on trying to solve some of the problems my illness brought on.			1 2 3	4 5
30.	Depended on others to cheer me up and make me feel better.			1 2 3	4 5

**SECTION B: DEALING WITH ILLNESS (Continued)**

1= Never      2= Rarely      3= Sometimes      4= Often      5= Always



		Never				Always
31.	Used some kind of relaxation technique (e.g. hypnosis, imagery, and meditation)	1	2	3	4	5
32.	Accepted the situation and got on with doing what needed to be done.		1	2	3	4 5
33.	Felt that it was my doctor's responsibility to make treatment decisions for me.		1	2	3	4 5
34.	Tried to understand what brought on my illness.		1	2	3	4 5
35.	Tried to maintain/ use positive thinking (kept a positive attitude).	1	2	3	4	5
36.	I was assertive (with medical staff, family, friends) about what I thought was best for me.	1	2	3	4	5
37.	Tried to understand how other people in this situation were thinking or feeling.	1	2	3	4	5
38.	Released my feelings somehow (e.g. cried, yelled, laughed) instead of holding them in.	1	2	3	4	5
39.	Tried to find out more about my illness.		1	2	3	4 5
40.	Believed that there was nothing I could do but wait since only time would make a difference.		1	2	3	4 5

**SECTION B: DEALING WITH ILLNESS (Continued)**

1= Never      2= Rarely      3= Sometimes      4= Often      5= Always

		Never			Always	
41.	Went over the situation again and again in my head.	1	2	3	4	5
42.	Daydreamed about better times.	1	2	3	4	5
43.	Thought about how I could have done things differently.	1	2	3	4	5
44.	Resigned myself to the situation since nothing could be done about it.	1	2	3	4	5
45.	I had trust (faith, respect, belief) in my doctor's medical knowledge and technical skills.	1	2	3	4	5
46.	Thought a lot about what is really important in my life.	1	2	3	4	5
47.	Worked on reaching a bargain or compromise to change things.	1	2	3	4	5
48.	Bought something or did something special for myself.	1	2	3	4	5
49.	Tried to work together with my doctor to decide what is best for me (i.e. established a collaborative relationship with my doctor).	1	2	3	4	5
50.	Thought about how much better off I am than some other people in my situation.	1	2	3	4	5

**SPIRITUAL- BASED SUPPORT GROUP INTERVENTION (DOD)**  
**Post Test**

**STUDY ID NUMBER:** \_\_\_\_\_

**SSN (last 4 digits)**    \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_

**Revised – February 14, 2006**

## **SECTION A: PROFILE OF MOOD STATES (MCNAIR ET AL., 1971)**

Below is a list of words that describe feelings people have. Please read each one carefully. Circle the answer which best describes: **How you have been feeling during the past week including today?**

0= Not at all                      1= A little bit                      2= Moderately  
3= Quite a bit                      4= Extremely

	Not at all				Extremely
1. Friendly	0	1	2	3	4
2. Tense	0	1	2	3	4
3. Angry	0	1	2	3	4
4. Worn Out	0	1	2	3	4
5. Unhappy	0	1	2	3	4
6. Clear-headed	0	1	2	3	4
7. Lively	0	1	2	3	4
8. Confused	0	1	2	3	4
9. Sorry for things done	0	1	2	3	4
10. Shaky	0	1	2	3	4
11. Listless	0	1	2	3	4
12. Peeved	0	1	2	3	4
13. Considerate	0	1	2	3	4
14. Sad	0	1	2	3	4

**SECTION A: PROFILE OF MOOD STATES (Continued)****How you have been feeling during the past week including today?**

0= 3=	Not at all Quite a bit	1= 4=	A little bit Extremely	2=	Moderately	
15.	Active	0	1	2	3	4
16.	On edge	0	1	2	3	4
17.	Grouchy	0	1	2	3	4
18.	Blue	0	1	2	3	4
19.	Energetic	0	1	2	3	4
20.	Panicky	0	1	2	3	4
21.	Hopeless	0	1	2	3	4
22.	Relaxed	0	1	2	3	4
23.	Unworthy	0	1	2	3	4
24.	Spiteful	0	1	2	3	4
25.	Sympathetic	0	1	2	3	4
26.	Uneasy	0	1	2	3	4
27.	Restless	0	1	2	3	4
28.	Unable to concentrate	0	1	2	3	4
29.	Fatigued	0	1	2	3	4
30.	Helpful	0	1	2	3	4

**SECTION A: PROFILE OF MOOD STATES (Continued)****How you have been feeling during the past week including today?**

0=	Not at all	1=	A little bit	2=	Moderately
3=	Quite a bit	4=	Extremely		
31. Annoyed	0	1	2	3	4
32. Discouraged	0	1	2	3	4
33. Resentful	0	1	2	3	4
34. Nervous	0	1	2	3	4
35. Lonely	0	1	2	3	4
36. Miserable	0	1	2	3	4
37. Muddled	0	1	2	3	4
38. Cheerful	0	1	2	3	4
39. Bitter	0	1	2	3	4
40. Exhausted	0	1	2	3	4
41. Anxious	0	1	2	3	4
42. Ready to fight	0	1	2	3	4
43. Good natured	0	1	2	3	4
44. Gloomy	0	1	2	3	4
45. Desperate	0	1	2	3	4

**SECTION A: PROFILE OF MOOD STATES (Continued)**

**How you have been feeling during the past week including today?**

0= Not at all                      1= A little bit                      2= Moderately  
3= Quite a bit                      4= Extremely

46. Sluggish	0	1	2	3	4
47. Rebellious	0	1	2	3	4
48. Helpless	0	1	2	3	4
49. Weary	0	1	2	3	4
50. Bewildered	0	1	2	3	4
51. Alert	0	1	2	3	4
52. Deceived	0	1	2	3	4
53. Furious	0	1	2	3	4
54. Efficient	0	1	2	3	4
55. Trusting	0	1	2	3	4
56. Full of pep	0	1	2	3	4
57. Bad-tempered	0	1	2	3	4
58. Worthless	0	1	2	3	4
59. Forgetful	0	1	2	3	4
60. Carefree	0	1	2	3	4

**SECTION A: PROFILE OF MOOD STATES (Continued)**

**How you have been feeling during the past week including today?**

0= Not at all                      1= A little bit                      2= Moderately  
3= Quite a bit                      4= Extremely

61. Terrified	0	1	2	3	4
62. Guilty	0	1	2	3	4
63. Vigorous	0	1	2	3	4
64. Uncertain about things	0	1	2	3	4
65. Bushed	0	1	2	3	4

**SECTION B: DEALING WITH ILLNESS (FAWZY, ET AL., 1990)**

The following is a list of things people do to deal with problems in their lives. Which of these things have you used recently to help deal with your illness?

1= Never                      2= Rarely                      3= Sometimes  
4= Often                      5= Always

	Never				Always
1. Thought about my illness but tried not to let it overly upset or overwhelm me.	1	2	3	4	5
2. Tried to keep others from knowing how I was feeling.	1	2	3	4	5
3. Prayed hard for a good ending to the situation.	1	2	3	4	5
4. Thought about it one day at a time.	1	2	3	4	5

**SECTION B: DEALING WITH ILLNESS (Continued)**

1= Never                      2= Rarely                      3= Sometimes



4= Often

5= Always

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 5. Went out more socially.  | 1 | 2 | 3 | 4 | 5 |
| 6. Accepted the reality of my diagnosis but did not automatically accept a poor outlook.  | 1 | 2 | 3 | 4 | 5 |
| 7. Talked to people just to be able to talk about it.                                     | 1 | 2 | 3 | 4 | 5 |
| 8. Thought about the positive changes in me since the illness.                            | 1 | 2 | 3 | 4 | 5 |
| 9. Went to a friend, or professional for advice on how to change things in the situation. | 1 | 2 | 3 | 4 | 5 |
| 10. Avoided being with people.  | 1 | 2 | 3 | 4 | 5 |
| 11. Tried to get someone, like a doctor, to do something about it.                        | 1 | 2 | 3 | 4 | 5 |
| 12. Took more vitamins and ate healthy foods.   | 1 | 2 | 3 | 4 | 5 |
| 13. Simply refused to even think about the situation as I just couldn't face it.          | 1 | 2 | 3 | 4 | 5 |
| 14. Went to a friend or a professional to help me feel better.                            | 1 | 2 | 3 | 4 | 5 |
| 15. Formed a plan of action in my mind.   | 1 | 2 | 3 | 4 | 5 |
| 16. Thought more about the meaning of life.   | 1 | 2 | 3 | 4 | 5 |

**SECTION B: DEALING WITH ILLNESS (Continued)**

1= Never

2= Rarely

3= Sometimes

4= Often

5= Always

17. Trusted my belief in God.	1	2	3	4	5
18. Talked with others in the same situation.	1	2	3	4	5
19. Prepared for the worst.	1	2	3	4	5
20. Turned to work or other activities to keep my mind off things.	1	2	3	4	5
21. Enjoyed everyday things more than I used to.	1	2	3	4	5
22. Developed myself as a person.	1	2	3	4	5
23. Exercised more than usual.	1	2	3	4	5
24. Drank more alcohol than usual.	1	2	3	4	5
25. Ate more than usual.	1	2	3	4	5
26. Smoked more than usual.	1	2	3	4	5
27. Took prescription/ illegal drugs more than usual.	1	2	3	4	5
28. Slept more than usual.	1	2	3	4	5
29. Worked on trying to solve some of the problems my illness brought on.	1	2	3	4	5
30. Depended on others to cheer me up and make me feel better.	1	2	3	4	5

### **SECTION B: DEALING WITH ILLNESS (Continued)**

1= Never                      2= Rarely                      3= Sometimes  
4= Often                      5= Always

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 31. Used some kind of relaxation technique (e.g. hypnosis, imagery, and meditation)              | 1 | 2 | 3 | 4 | 5 |
| 32. Accepted the situation and got on with doing what needed to be done.                         | 1 | 2 | 3 | 4 | 5 |
| 33. Felt that it was my doctor's responsibility to make treatment decisions for me.              | 1 | 2 | 3 | 4 | 5 |
| 34. Tried to understand what brought on my illness.  | 1 | 2 | 3 | 4 | 5 |
| 35. Tried to maintain/ use positive thinking (kept a positive attitude).                         | 1 | 2 | 3 | 4 | 5 |
| 36. I was assertive (with medical staff, family, friends) about what I thought was best for me.  | 1 | 2 | 3 | 4 | 5 |
| 37. Tried to understand how other people in this situation were thinking or feeling.             | 1 | 2 | 3 | 4 | 5 |
| 38. Released my feelings somehow (e.g. cried, yelled, laughed) instead of holding them in.       | 1 | 2 | 3 | 4 | 5 |
| 39. Tried to find out more about my illness.   | 1 | 2 | 3 | 4 | 5 |
| 40. Believed that there was nothing I could do but wait since only time would make a difference. | 1 | 2 | 3 | 4 | 5 |

**SECTION B: DEALING WITH ILLNESS (Continued)**

1= Never                      2= Rarely                      3= Sometimes  
4= Often                      5= Always

41. Went over the situation again and again in my head.	1	2	3	4	5
42. Daydreamed about better times.	1	2	3	4	5
43. Thought about how I could have done things differently.	1	2	3	4	5
44. Resigned myself to the situation since nothing could be done about it.	1	2	3	4	5
45. I had trust (faith, respect, belief) in my doctor's medical knowledge and technical skills.	1	2	3	4	5
46. Thought a lot about what is really important in my life.	1	2	3	4	5
47. Worked on reaching a bargain or compromise to change things.	1	2	3	4	5
48. Bought something or did something special for myself.	1	2	3	4	5
49. Tried to work together with my doctor to decide what is best for me (i.e. established a collaborative relationship with my doctor).	1	2	3	4	5
50. Thought about how much better off I am than some other people in my situation.	1	2	3	4	5

**SECTION C: CONCURRENT STRESS INDEX (SMILKSTEIN & ZIMLICK, 1990)**

How would you rate the stress in your life now? "Stress" in this questionnaire refers to feelings of distress, tension or anxiety. Circle the number under the heading that seems to

apply to you. All questions refer to events during the past 12 months.

For each question, circle only one number.

0=Never

1=Hardly Ever

2=Some of the Time

3=Almost Always

4=Always

5=Not Applicable (N/A)

	Never					N/A
1. If you work outside the home, stress at work.	0	1	2	3	4	5
2. If you go to school, stress at school.	0	1	2	3	4	5
3. If during the past year you have moved, stress due to move.	0	1	2	3	4	5
4. Stress due to concern about you health.	0	1	2	3	4	5
5. Stress due to concern about sex.	0	1	2	3	4	5
6. Stress with money or financial problems.	0	1	2	3	4	5
7. Stress at home.	0	1	2	3	4	5
8. If you are a parent, stress as a parent.	0	1	2	3	4	5

### **SECTION C: CONCURRENT STRESS INDEX (Continued)**

0=Never

1=Hardly Ever

2=Some of the Time

3=Almost Always  
4=Always  
5=Not Applicable

- |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|
| 9. If you are married or living with a partner, stress with spouse or partner.                    | 0 | 1 | 2 | 3 | 4 | 5 |
| 10. If during the past year you had a death in your family, stress due to death.                  | 0 | 1 | 2 | 3 | 4 | 5 |
| 11. If during the past year you had a death of a friend, stress due to death of a friend.         | 0 | 1 | 2 | 3 | 4 | 5 |
| 12. If during the past year you had a divorce or separation, stress due to divorce or separation. | 0 | 1 | 2 | 3 | 4 | 5 |
| 13. If you work, stress due to boss or supervisor.  | 0 | 1 | 2 | 3 | 4 | 5 |
| 14. If a member of your family is away from home, stress due to member being away.                | 0 | 1 | 2 | 3 | 4 | 5 |
| 15. If during the past year you have experienced the loss of a pet, stress due to loss of pet.    | 0 | 1 | 2 | 3 | 4 | 5 |

**SECTION C: CONCURRENT STRESS INDEX (Continued)**

0=Never  
1=Hardly Ever  
2=Some of the Time  
3=Almost Always  
4=Always  
5=Not Applicable

16. If during the past year you were victim of a crime or you had a legal problem, stress due to crime or legal problem.	0	1	2	3	4	5
17. If you have a close friend, stress due to relationship with friend.	0	1	2	3	4	5
18. If during the last year you have had an injury or illness problem, stress due to injury or illness.	0	1	2	3	4	5
19. If you are pregnant, stress due to pregnancy.	0	1	2	3	4	5
20. During the past year, if you have had a family member arrested, stress due to arrest of family member.	0	1	2	3	4	5
21. During the past year, a family member has been victim of a crime, stress due to family member being victimized.	0	1	2	3	4	5
22. During the past year, a family member has been involved with drugs, stress due to family member's involvement with drugs.	0	1	2	3	4	5

**SECTION C: CONCURRENT STRESS INDEX (Continued)**

0=Never  
1=Hardly Ever  
2=Some of the Time  
3=Almost Always  
4=Always  
5=Not Applicable

23. During the past year, change in health of a family member, stress due to change in health of family member.      0      1      2      3      4      5

24. During the past year, change in living conditions, stress due to change in living conditions.      0      1      2      3      4      5

**SECTION D:      SOCIO-DEMOGRAPHIC DATA (GARY, BROWN, ET AL, 1989)**

D1.    Where were you born?

\_\_\_\_\_  
City/state/country

D2.    When were you born?

\_\_\_\_/\_\_\_\_/\_\_\_\_  
month      day      year

D3.    Are you currently married, divorced, separated, widowed, or never married?

6. [ ] Married

7. [ ] Divorced

8. [ ] Separated

9. [ ] Widowed

10.[ ] Never married

**SECTION D:      SOCIO-DEMOGRAPHIC DATA (Continued)**

D4.    How many grades or years of school have you finished?  
(Check the highest grade completed)

**Elementary**

01 02 03 04 05 06 07 08

**High School**

09 10 11 12

**College**

13 14 15 16

**Graduate**

17+



D5. Are you currently employed.....

4. ☐ Employed, how many hours per week \_\_\_\_\_

Has your illness affected your employment? Explain

\_\_\_\_\_  
\_\_\_\_\_

5. ☐ Medical Leave

6. ☐ Not employed

(a) If not employed, are you

1. unemployed, looking for work

2. retired

3. student

4. housewife/homemaker

5. disabled

6. other \_\_\_\_\_

(b) Are you not working because of your illness?

1. ☐ yes

2. ☐ no

D6. What do you consider your main occupation?

---

**SECTION D: SOCIO-DEMOGRAPHIC DATA (Continued)**

D7. Summary:

Total number of persons in household \_\_\_\_\_

Total number of adults 18 years + \_\_\_\_\_

Total number of children 0-17 years. \_\_\_\_\_

Below are listed questions about the people who live in the household with you. Please indicate the name, gender, age, and relationship to you.

**D8. Use the codes below to complete the household list:**

Relationships:

10.HU= husband/partner

11.SO= son

12.DA= daughter

13.SI= sister

14.UN= uncle

15.NP= nephew

16.GC= grandchild

17.GM= grandmother

18.NR= non-relative

10. FA= father

11. MO= mother

12. BR= brother

13. AT= aunt

14. NC= niece

15. CO= cousins

16. GF= grandfather

17. OR= other relative

Gender: 1) M= male 2) F= female

First name only	Relationship	Gender	Age
Household Member 1			
Household Member 2			
Household Member 3			
Household Member 4			

**SECTION D: SOCIO-DEMOGRAPHIC DATA (Continued)**

First name only	Relationship	Gender	Age
Household Member 5			
Household Member 6			
Household Member 7			

1. The first part of the document is a header section containing the title "The Role of the Teacher in the 21st Century" and the author's name "Dr. Jane Smith".

\_\_\_\_\_

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1. ☐ Self      2. ☐ Other, specify\_\_\_\_\_

Number

**SECTION D: SOCIO-DEMOGRAPHIC DATA (Continued)**

D11. Are there other people for whom you provide regular assistance or care? (Example: elderly parents, older relatives, children, grandchildren, adopted children)

Relationship

---

---

---

---

---

(b). ☐ No

D6. How many children have you given birth to?

☐ \_\_\_\_\_  
number

☐ NONE

D6b. How old were you when you gave birth to your first child?

Age \_\_\_\_\_

**SECTION E: CANCER BACKGROUND AND HISTORY (BROWN & SIMON, 1995)**

E1. Since we last spoke to you, have you been diagnosed with any other types of cancer?

3. ☐ yes

If yes, what type?

\_\_\_\_\_ Recurrent Breast  
\_\_\_\_\_ Lung  
\_\_\_\_\_ Colon  
\_\_\_\_\_ Ovarian  
\_\_\_\_\_ Other

4. ☐ no

E2. Since we last spoke to you, have any of your blood relatives had breast cancer?

1. ☐ yes

2. ☐ no

Skip to Section E8.

a. ☐ Sister 1

1. Yes

2. No

3. Don't know

b. ☐ Sister 2

1. Yes

2. No

3. Don't know

c. ☐ Sister 3

1. Yes

2. No

3. Don't know

- d. ☐ Sister 4                      1.Yes              2.No              3. Don't know
- e. ☐ Mother                      1.Yes              2.No              3. Don't know
- f. ☐ Paternal Aunt              1.Yes              2.No              3. Don't know
- g. ☐ Maternal Aunt              1.Yes              2.No              3. Don't know
- h. ☐ Paternal  
Grandmother              1.Yes              2.No              3. Don't know
- i. ☐ Maternal  
Grandmother              1.Yes              2.No              3. Don't know

**SECTION E:      CANCER BACKGROUND AND HISTORY (Continued)**

- j. ☐ Daughter                      1.Yes              2.No              3. Don't know
- k. ☐ Daughter                      1.Yes              2.No              3. Don't know
- l. ☐ Other                      1.Yes              2.No              3. Don't know

E8. In terms of your overall health, during the past 12 months, have you had any of the following: **(CHECK ALL THAT APPLY)**

21. ☐ Poor vision
22. ☐ Poor hearing
23. ☐ Respiratory infection
24. ☐ Convalescence from surgery-other than related to breast  
cancer
25. ☐ Injury/ deformity
26. ☐ Arthritis or Rheumatism
27. ☐ Heart disease
28. ☐ High blood pressure (hypertension)
29. ☐ Stroke
30. ☐ Diabetes
31. ☐ Chronic lung disease (emphysema, asthma)
32. ☐ Ulcers
33. ☐ Liver problem
34. ☐ Kidney problem
35. ☐ Nervous condition
36. ☐ Allergies

- 37.[ ] Sickle cell anemia  
 38.[ ] HIV/AIDS  
 39.[ ] Other (specify) \_\_\_\_\_  
 40.[ ] None

## **SECTION F: SPIRITUAL WELL BEING (ELLISON & PALOUTZIAN, 1982)**

For each of the following statements circle the choice that best indicates the extent of your agreement or disagreement as it describes your personal experience.

6=Strongly Agree  
 5=Moderately Agree  
 4=Agree

3=Disagree  
 2=Moderately Disagree  
 1=Strongly Disagree

- |  |   |   |   |   |   |   |
|--|---|---|---|---|---|---|
| 1. I don't find much satisfaction in prayer with God.                          | 6 | 5 | 4 | 3 | 2 | 1 |
| 2. I don't know who I am, where I came from or where I am going.               | 6 | 5 | 4 | 3 | 2 | 1 |
| 3. I believe that God loves me and cares about me.                             | 6 | 5 | 4 | 3 | 2 | 1 |
| 4. I feel that life is a positive experience.                                  | 6 | 5 | 4 | 3 | 2 | 1 |
| 5. I believe that God is impersonal and not interested in my daily situations. | 6 | 5 | 4 | 3 | 2 | 1 |
| 6. I feel unsettled about my future.   | 6 | 5 | 4 | 3 | 2 | 1 |
| 7. I have a personally meaningful relationship with God.                       | 6 | 5 | 4 | 3 | 2 | 1 |

- |  |   |   |   |   |   |   |
|--|---|---|---|---|---|---|
| 8. I feel very fulfilled and satisfied with life.                          | 6 | 5 | 4 | 3 | 2 | 1 |
| 9. I don't get much personal strength and support from my God.             | 6 | 5 | 4 | 3 | 2 | 1 |
| 10. I feel a sense of well-being about the direction my life is headed in. | 6 | 5 | 4 | 3 | 2 | 1 |

**SECTION E:      CANCER BACKGROUND AND HISTORY (Continued)**

- |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|
| 11. I believe that God is concerned about my problems.              | 6 | 5 | 4 | 3 | 2 | 1 |
| 12. I don't enjoy much about life.                                  | 6 | 5 | 4 | 3 | 2 | 1 |
| 13. I don't have a personally satisfying relationship with God.     | 6 | 5 | 4 | 3 | 2 | 1 |
| 14. I feel good about my future.                                    | 6 | 5 | 4 | 3 | 2 | 1 |
| 15. My relationship with God helps me not feel lonely.              | 6 | 5 | 4 | 3 | 2 | 1 |
| 16. I feel that life is full of conflict and unhappiness.           | 6 | 5 | 4 | 3 | 2 | 1 |
| 17. I feel most fulfilled when I'm in close communion with God.     | 6 | 5 | 4 | 3 | 2 | 1 |
| 18. Life doesn't have much meaning.                                 | 6 | 5 | 4 | 3 | 2 | 1 |
| 19. My relationship with God contributes to my sense of well-being. | 6 | 5 | 4 | 3 | 2 | 1 |
| 20. I believe there is some real purpose for my life.               | 6 | 5 | 4 | 3 | 2 | 1 |

## **SECTION H: MENTAL WELL BEING (CES-D (RADLOFF, 1977))**

I will read a list of ways you may have felt or behaved. Please indicate how often you have felt or behaved this way **during the past week:**  
rarely or none of the time; some or little of the time; occasionally or a moderate amount of time; or most of the time.

RARELY OR NONE OF THE TIME (LESS THAN 1 DAY) 0

SOME OR LITTLE OF THE TIME (1-2 DAYS) 1

OCCASIONALLY OR A MODERATE AMOUNT OF TIME 2  
(3-4 DAYS)

MOST OR ALL OF THE TIME (5-7 DAYS) 3

- |  |   |   |   |   |
|--|---|---|---|---|
| a. I was bothered by things that usually don't bother me.                              | 0 | 1 | 2 | 3 |
| b. I did not feel like eating; my appetite was poor.                                   | 0 | 1 | 2 | 3 |
| c. I felt that I could not shake off the blues even with help from family and friends. | 0 | 1 | 2 | 3 |
| d. I felt that I was just as good as other people.                                     | 0 | 1 | 2 | 3 |
| e. I had trouble keeping my mind on what I was doing.                                  | 0 | 1 | 2 | 3 |
| f. I felt depressed.   | 0 | 1 | 2 | 3 |
| g. I felt that everything I did was an effort.   | 0 | 1 | 2 | 3 |
| h. I felt hopeful about the future.  | 0 | 1 | 2 | 3 |
| i. I thought my life had been a failure.   | 0 | 1 | 2 | 3 |
| j. I felt fearful.   | 0 | 1 | 2 | 3 |
| k. My sleep was restless.  | 0 | 1 | 2 | 3 |
| l. I was happy.  | 0 | 1 | 2 | 3 |



**SECTION H: MENTAL WELL BEING (CES-D (Continued))**

RARELY OR NONE OF THE TIME (LESS THAN 1 DAY) 0

SOME OR LITTLE OF THE TIME (1-2 DAYS) 1

OCCASIONALLY OR A MODERATE AMOUNT OF TIME (3-4 DAYS) 2

MOST OR ALL OF THE TIME (5-7 DAYS) 3

m. I talked less than usual. 0 1 2 3

n. I felt lonely. 0 1 2 3

o. People were unfriendly. 0 1 2 3

p. I enjoyed life. 0 1 2 3

q. I had crying spells. 0 1 2 3

r. I felt sad. 0 1 2 3

s. I felt that people dislike me. 0 1 2 3

t. I couldn't not get "going". 0 1 2 3

## **SECTION I: ACCESSIBILITY**

- I1. What is the TOTAL annual income of ALL the persons living in your household, that is considering all sources such as jobs, Social Security, retirement income, salaries, wages, unemployment compensation, profits, interest, and so on?

- 15.[ ] Less than \$5,000
- 16.[ ] \$ 5,000- \$9,999
- 17.[ ] \$10,000- \$14,999
- 18.[ ] \$15,000- \$19,999
- 19.[ ] \$20,000- \$24,999
- 20.[ ] \$25,000- \$29,999
- 21.[ ] \$30,000- \$39,999
- 22.[ ] \$40,000- \$49,999
- 23.[ ] \$50,000- \$59,999
- 24.[ ] \$60,000- \$69,999
- 25.[ ] \$70,000- \$79,999
- 26.[ ] \$80,000- \$89,999
- 27.[ ] \$90,000- \$99,999
- 28.[ ] \$10,0000 or more

- I2. What is the **Your** personal annual income, that is considering all sources such as jobs, Social Security, retirement income, salaries, wages, unemployment compensation, profits, interests, etc.

- 29.[ ] Less than \$5,000
- 30.[ ] \$ 5,000- \$9,999
- 31.[ ] \$10,000- \$14,999
- 32.[ ] \$15,000- \$19,999
- 33.[ ] \$20,000- \$24,999
- 34.[ ] \$25,000- \$29,999
- 35.[ ] \$30,000- \$39,999
- 36.[ ] \$40,000- \$49,999
- 37.[ ] \$50,000- \$59,999
- 38.[ ] \$60,000- \$69,999
- 39.[ ] \$70,000- \$79,999
- 40.[ ] \$80,000- \$89,999
- 41.[ ] \$90,000- \$99,999
- 42.[ ] \$100000 or more

**SECTION I: ACCESSIBILITY (Continued)**

I3. Do you have access to a car or have transportation when you need to visit the doctor for breast cancer treatment?

2. ☐ Yes

2. ☐ No, If no, is this an obstacle to your receiving treatment or routine health care? \_\_\_\_\_

I4. Do you have health insurance coverage for yourself?

3. ☐ Yes

If yes, what type \_\_\_\_\_  
Blue Cross/ Blue Shield, Health Plus, DMC, Other

4. ☐ No

I5. Are you covered by MEDICAID? (NOT Medicare)

4. ☐ Yes

5. ☐ No

6. ☐ Don't Know

I6. Does your health insurance cover all the costs of your medical treatment for breast cancer?

4. ☐ Yes, all costs

5. ☐ Yes, partial costs

6. ☐ No

**SECTION J: EXTERNAL RESOURCES AND SOCIAL SUPPORT (GARY & BROWN, ET. AT, 1989)**

J1a. How many total family members who you see or talk with regularly live nearby, that is less than 50 miles away?

---

J1b. How often do people in your family – including children, grandparents, uncles, in-laws, and so on- help you out?

- ☐ Very Often
- ☐ Fairly Often
- ☐ Not too often
- ☐ Never (If Never, Skip to J5)

**Only If Relatives Help**

J2. How much help are your family members to you?

- ☐ A great deal of help
- ☐ A lot of help
- ☐ Only a little help

J3. In what ways are your family members most helpful to you? Please specify?

---

---

---

J4. How satisfied are you with the help you receive from your family members?

- ☐ Very satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied or dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Very dissatisfied

**SECTION J: EXTERNAL RESOURCES AND SOCIAL SUPPORT (Continued)**

J5. How many total friends who you see or talk with regularly live nearby, that is less than 50 miles away?

\_\_\_\_\_

J6. How often do your friends help out?

☐ Very Often

☐ Fairly Often

☐ Not too often

☐ Never

(If Never, Skip to J10)

**Only If Friends Help**

J7. How much help are your friends to you?

☐ A great deal of help

☐ A lot of help

☐ Only a little help

J8. In what ways are your friends most helpful to you? Please specify?

\_\_\_\_\_

\_\_\_\_\_

J9. How satisfied are you with the help you receive from your friends?

☐ Very satisfied

☐ Somewhat satisfied

☐ Neither satisfied or dissatisfied

☐ Somewhat dissatisfied

☐ Very dissatisfied

**SECTION J: EXTERNAL RESOURCES AND SOCIAL SUPPORT (Continued)**

J10. Is there anyone to whom you can really open up about your most private feelings without having to hold back?

1. ☐ Yes, who is this? \_\_\_\_\_  
(relationship) \_\_\_\_\_

2. ☐ No

J11. Has having cancer in any way affected your family life or the relationships among family members?

c. ☐ Yes, in what ways?

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

d. ☐ No

J12. Since being diagnosed with breast cancer, have you seen or sought counseling with a social worker, psychologist, psychiatrist or any other mental health professional?

☐ Yes, explained \_\_\_\_\_

☐ No

J13. Are you currently seeing a social worker, psychologist, psychiatrist or any other mental health professional?

☐ Yes

☐ No

### **SECTION K: STRESSES AND PROBLEM (HOLMES & RAHE, 1975)**

This section deals with stresses and problems you may have had.

K1. Within the PAST 12 MONTHS, have you experienced:

**Record by placing an X in the right column for the events that the Respondent has experienced.**

During the past  
12 months

- (1) an illness or injury which:
  - (a) kept you in bed a week or more,  
or took you to the hospital? \_\_\_\_\_
  - (b) an injury which was less serious than  
I just described? \_\_\_\_\_
- (2) a major change in eating habits? \_\_\_\_\_
- (3) a major change in sleeping habits? \_\_\_\_\_
- (4) a change in your usual type and/or  
amount of recreation? \_\_\_\_\_
- (5) major dental work? \_\_\_\_\_

**Note for respondents who are not working (Skip to 10)**  
Have you:

- (6) changed to a new type of work? \_\_\_\_\_
- (7) changed your work hours or conditions? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

Within the PAST 12 MONTHS, have you experienced:  
**Record by placing an X in the right column for the events that the Respondent has experienced.**

During the past 12 months

- (8) had a change in your responsibilities at work: \_\_\_\_\_
- (a) more responsibilities? \_\_\_\_\_
- (b) less responsibilities? \_\_\_\_\_
- (c) promotion? \_\_\_\_\_
- (d) demotion? \_\_\_\_\_
- (e) transfer? \_\_\_\_\_
- (9) experienced troubles at work: \_\_\_\_\_
- (a) with your boss? \_\_\_\_\_
- (b) with co-workers? \_\_\_\_\_
- (c) with persons under your supervision? \_\_\_\_\_
- (d) other work troubles? \_\_\_\_\_
- (10) experienced a major business readjustment? \_\_\_\_\_
- (11) retired? \_\_\_\_\_
- (12) experienced being: \_\_\_\_\_
- (a) fired from work? \_\_\_\_\_
- (b) laid off from work? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

Within the PAST 12 MONTHS, have you experienced:

**Record by placing an X in the right column for the events that the Respondent has experienced.**

During the past  
12 months



- |      |  |       |
|------|--|-------|
| (13) | taken courses by mail or studied at home to help you in your work?   | _____ |
| (14) | a change in residence:   |       |
|      | (a) a move within the same town or city?   | _____ |
|      | (b) a move to a different town, city or state?   | _____ |
| (15) | a change in family “get-togethers” ?   | _____ |
| (16) | a major change in the health or behavior of a family member (illness, accidents, drug or disciplinary problems, etc.)? | _____ |
| (17) | major change in your living conditions (home improvements or a decline in your home or neighborhood)?                  | _____ |
| (18) | the death of a spouse?   | _____ |
| (19) | the death of a:  |       |
|      | (a) child?   | _____ |
|      | (b) brother or sister?   | _____ |
|      | (c) parent?  |       |
|      | (d) other close family member?   | _____ |
| (20) | the death of a close friend?   | _____ |

**SECTION K: STRESSES AND PROBLEM (Continued)**

Within the PAST 12 MONTHS, have you experienced:  
**Record by placing an X in the right column for the events that the Respondent has experienced.**

During the past 12 months

(21) change in the marital status of your parents:

(a) divorce? \_\_\_\_\_

(b) remarriage? \_\_\_\_\_

(c) legally separated? \_\_\_\_\_

**NOTE: (RESPONDENTS WHO ARE MARRIED GO TO  
QUESTIONS 22 TO 28.  
FOR PERSONS NEVER MARRIED, GO TO 29)**

(22) marriage? \_\_\_\_\_

(23) a change in arguments with your spouse? \_\_\_\_\_

(24) in- law problems? \_\_\_\_\_

(25) a separation from spouse:

(a) due to work? \_\_\_\_\_

(b) due to marital problems? \_\_\_\_\_

(26) a reconciliation with spouse? \_\_\_\_\_

(27) a divorce? \_\_\_\_\_

(28) your spouse beginning or ceasing work  
outside the home? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

Within the PAST 12 MONTHS, have you experienced:

**Record by placing an X in the right column for the events that the  
Respondent has experienced.**

During the past  
12 months

(29) a gain of a new family member:

(a) birth of a child? \_\_\_\_\_

(b) adoption of a child? \_\_\_\_\_

(c) a relative moving in with you? \_\_\_\_\_

(30) you becoming pregnant? \_\_\_\_\_

(31) you having a miscarriage or abortion? \_\_\_\_\_

NOTE:

**(QUESTIONS 32 AND 33 CONCERN CHILDREN. FOR PERSONS WHO DO NOT HAVE CHILDREN, GO TO 34)**

(32) a child leaving home:

(a) due to marriage? \_\_\_\_\_

(b) to attend college? \_\_\_\_\_

(c) for other reasons? \_\_\_\_\_

(33) birth of a grandchild? \_\_\_\_\_

(34) a major personal achievement? \_\_\_\_\_

(35) a change in your personal habits  
(your dress, friends, lifestyles, etc.)? \_\_\_\_\_

(36) sexual difficulties? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

Within the PAST 12 MONTHS, have you experienced:

**Record by placing an X in the right column for the events that the Respondent has experienced.**

During the past  
12 months

- (37) beginning or ceasing school or college? \_\_\_\_\_
- (38) a change of school or college? \_\_\_\_\_
- (39) a vacation? \_\_\_\_\_
- (40) a change in your religious beliefs? \_\_\_\_\_
- (41) a change in your social activities  
(clubs, movies, visiting)? \_\_\_\_\_
- (42) a minor violation of the law? \_\_\_\_\_
- (43) legal troubles resulting in your  
being held in jail? \_\_\_\_\_
- (44) a change in your political beliefs? \_\_\_\_\_
- (45) a new, close, personal relationship? \_\_\_\_\_
- (46) an engagement to marry? \_\_\_\_\_
- (47) a "falling out" of a close personal  
relationship? \_\_\_\_\_
- (48) girlfriend (or boyfriend) problems? \_\_\_\_\_
- (49) a loss or damage of personal property? \_\_\_\_\_
- (50) an accident? \_\_\_\_\_

**SECTION K: STRESSES AND PROBLEM (Continued)**

Within the PAST 12 MONTHS, have you experienced:  
**Record by placing an X in the right column for the events that the  
Respondent has experienced.**

- |                                      |                              |       |
|--------------------------------------|------------------------------|-------|
|                                      | During the past<br>12 months |       |
| (51) a major decision regarding your |                              | _____ |

immediate future?

Have you:

- (52) taken on a moderate purchase, such as a T.V., car, freezer, etc.) \_\_\_\_\_
- (53) taken on a major purchase or a mortgage loan, such as a home, business, property, etc.? \_\_\_\_\_
- (54) experienced a foreclosure on a mortgage or loan? \_\_\_\_\_
- (55) experienced a major change in finances:
  - (a) increased income? \_\_\_\_\_
  - (b) decreased income? \_\_\_\_\_
  - (c) credit rating difficulties? \_\_\_\_\_

## **SECTION L: RELIGIOUS PRACTICES & BEHAVIOR**

L1. What is your religious denominational preference? (Check one)

2. ☐ None

2. ☐ Protestant, (specify) \_\_\_\_\_

3. ☐ Jewish

4. ☐ Catholic

5. ☐ Muslim (Islamic)

6. ☐ Other, (specify) \_\_\_\_\_

L2. Using the expressions- very often, often, sometimes, almost never, and never, please describe ways in which you are involved in religion.

1- Very often

2- Often

3- Sometimes

4- Almost never

5- Never

2. I attend religious crusades, revival meetings or missions.	1	2	3	4	5
2. I attend religious services.	1	2	3	4	5
3. I listen to religious services on the radio or TV or internet.	1	2	3	4	5
4. I sometimes pray, either privately or with family.	1	2	3	4	5
5. I listen to religious music.	1	2	3	4	5
6. Ideas I have learned from religion sometimes help me understand my own life.	1	2	3	4	5

**SECTION L: RELIGIOUS PRACTICES & BEHAVIOR (Continued)**

4- Very often

4- Almost never

5- Often

5- Never

6- Sometimes

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 7. I contribute money to church<br>(or other religious institutions).       | 1 | 2 | 3 | 4 | 5 |
| 8. I regularly take part in various<br>religious organizations.             | 1 | 2 | 3 | 4 | 5 |
| 9. I feel that the church or religion<br>helps me in getting ahead in life. | 1 | 2 | 3 | 4 | 5 |
| 10. The religious beliefs I learned<br>when I was young still help me.      | 1 | 2 | 3 | 4 | 5 |

L3. How religious would you say you are?

- 7. ☐ very religious
- 8. ☐ somewhat religious
- 9. ☐ not very religious
- 10. ☐ not at all religious
- 11. ☐ don't know
- 12. ☐ refused

L4. Has your religious involvement changed since your diagnosis of breast cancer?

3. ☐ yes, how?

☐ increased? Explain \_\_\_\_\_

☐ decreased? Explain \_\_\_\_\_

4. ☐ no, remained the same

L5. To what extent has your religious involvement helped you deal with breast cancer?

- ☐ A great deal
- ☐ Somewhat
- ☐ No help

**SECTION L: RELIGIOUS PRACTICES & BEHAVIOR (Continued)**

L6. In the past year, have you gone to a minister, or elder for guidance when faced with a problem?

2. ☐ Yes

2. ☐ No (SKIP TO SECTION L7)

If yes, what kind of problem(s) have you discussed with these persons? (MARK ALL THAT APPLY)

1. ☐ Breast Cancer

2. ☐ Money

3. ☐ Job

4. ☐ Accident

5. ☐ Worry (anxiety)

6. ☐ Family

7. ☐ Spiritual

8. ☐ Marital

9. ☐ Divorce

10. ☐ Feeling low, depression

11. ☐ Other Health Issue (Specify) \_\_\_\_\_

12. ☐ Other Problem, (Specify) \_\_\_\_\_

L7. In dealing with your illness, how much or how frequently have you done or used the following?

1= Not at all

2= Somewhat

3= Quite a bit

4= A great deal

\_\_\_\_\_ A. Called a prayer partner

\_\_\_\_\_ B. Performed religious rituals such as saying the rosary

\_\_\_\_\_ C. Provide testimony about your illness

\_\_\_\_\_ D. Asked someone to pray for you

\_\_\_\_\_ E. Meditated

\_\_\_\_\_ F. Prayed by yourself

L7. In dealing with your illness, how much or how frequently have you



done or used the following?

- 1= Not at all
- 2= Somewhat
- 3= Quite a bit
- 4= A great deal

- \_\_\_\_\_ G. Prayed with others
- \_\_\_\_\_ H. Telephoned prayer line
- \_\_\_\_\_ I. Read or recited scriptures or inspirational verses
- \_\_\_\_\_ J. Listened to spirituals or other music, e.g. radio, Cds.
- \_\_\_\_\_ K. Watched religious programs on TV
- \_\_\_\_\_ L. Attended religious services
- \_\_\_\_\_ M. Attended religious retreat
- \_\_\_\_\_ N. Participated in testifying, witnessing, giving praise
- \_\_\_\_\_ O. Participated in a support group within the church
- \_\_\_\_\_ P. Participated in family activities
- \_\_\_\_\_ Q. Participated in Bible study classes/ groups
- \_\_\_\_\_ R. Attended revivals, prayer meetings
- \_\_\_\_\_ S. Read inspirational books
- \_\_\_\_\_ T. Talked to God, holy spirit, higher power
- \_\_\_\_\_ U. Kept a diary or journal
- \_\_\_\_\_ V. Received counseling from member of the clergy

## **SECTION M: FACT-B (VERSION 3) CELLA ET AL., 1993**

### **PHYSICAL WELL-BEING**

Below is a list of statements that other people with your illness have said are important. By circling one number per line, please indicate how true each statement has been for you during the past 7 days.

0= Not at all  
1= A little bit  
2= Somewhat  
3= Quite a bit  
4= Very much

	Not at all	A little bit	Some- what	Quite a bit	Very much
1. I have a lack of energy .....	0	1	2	3	4
2. I have nausea.....	0	1	2	3	4
3. Because of my physical condition, I have trouble meeting the needs of my family.....	0	1	2	3	4
4. I have pain.....	0	1	2	3	4
5. I am bothered by side effects of treatment...	0	1	2	3	4
6. I feel sick.....	0	1	2	3	4
7. I am forced to spend time in bed .....	0	1	2	3	4

### **SOCIAL/FAMILY WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much	
8. I feel distant from my friends.....		0	1	2	3	4
9. I get emotional support from my family....	0	1	2	3	4	
10. I get support from my friends and neighbors	0	1	2	3	4	
11. My family has accepted my illness.....	0	1	2	3	4	

**SECTION M: FACT-B (VERSION 3) (Continued)****SOCIAL/FAMILY WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much
12. Family communication about my illness... is poor	0	1	2	3	4
13. I feel close to my partner (or the person who is my main support).....	0	1	2	3	4
14. Have you been sexually active during the past year?.....	[ ] No [ ] Yes				
If yes: I am satisfied with my sex life.....	0	1	2	3	4

**FUNCTIONAL WELL-BEING**

	Not at all	A little bit	Some- what	Quite a bit	Very much
15. I am able to work (include work in home)..	0	1	2	3	4
16. My work (include work in home) is fulfilling.....	0	1	2	3	4
17. I am able to enjoy life.....	0	1	2	3	4
18. I have accepted my illness.....	0	1	2	3	4
19. I am sleeping well.....	0	1	2	3	4
20. I am enjoying the things I usually do for fun.....	0	1	2	3	4
21. I am content with the quality of my life right now.....	0	1	2	3	4

## EMOTIONAL WELL-BEING

	Not at all	A little bit	Some- what	Quite a bit	Very much
22. I feel sad.....	0	1	2	3	4
23. I am proud of how I'm coping with my illness.....	0	1	2	3	4
24. I am losing hope in the fight against my illness.....	0	1	2	3	4
25. I feel nervous.....	0	1	2	3	4
26. I worry about dying.....	0	1	2	3	4
27. I worry that my condition will get worse ...	0	1	2	3	4

## ADDITIONAL CONCERNS

	Not at all	A little bit	Some- what	Quite a bit	Very much
28. I have been short of breath .....	0	1	2	3	4
29. I am self-conscious about the way I dress....	0	1	2	3	4
30. My arms are swollen or tender.....	0	1	2	3	4
31. I feel sexually attractive.....	0	1	2	3	4
32. I have been bothered by hair loss.....	0	1	2	3	4
33. I worry about the risk of cancer in other family members.....	0	1	2	3	4

**SECTION N: HEALTH PROMOTION LIFESTYLE PROFILE (WALKER, SECHRIST & PENDER, 1987)**

N1. How frequently do you perform the following activities?

1=Never

2=Sometimes

3=Often

4=Routinely

		Never			Routinely	
1.	Check for cholesterol level	1	2	3	4	
2.	Report symptoms to M.D.	1	2	3	4	
3.	Read books about health	1	2	3	4	
4.	Question M.D. / second opinion		1	2	3	4
5.	Discuss health concerns	1	2	3	4	
6.	Check blood pressure	1	2	3	4	
7.	Seek information	1	2	3	4	
8.	Attend environmental programs	1	2	3	4	
9.	Observe body for changes	1	2	3	4	
10.	Attend health care programs	1	2	3	4	
11.	Do stretching exercise	1	2	3	4	
12.	Vigorous exercise 3 times per week	1	2	3	4	
13.	Supervised exercise programs	1	2	3	4	
14.	Recreational activities	1	2	3	4	
15.	Check pulse rate	1	2	3	4	
16.	Eat breakfast	1	2	3	4	

**SECTION N: HEALTH PROMOTION LIFESTYLE PROFILE (Continued)**

N1. How frequently do you perform the following activities?

1=Never

2=Sometimes

3=Often

4=Routinely

		Never			Routinely	
17.	Eat three meals daily	1	2	3	4	
18.	Use no preservatives	1	2	3	4	
19.	Read labels	1	2	3	4	
20.	Eat roughage/ fiber	1	2	3	4	
21.	Eat basic 4 foods groups	1	2	3	4	
22.	Discuss concerns/ problems	1	2	3	4	
23.	Spend daily relaxation time	1	2	3	4	
24.	Are aware of stress sources	1	2	3	4	
25.	Engage in meditation/relaxation		1	2	3	4
26.	Relax muscles before sleep	1	2	3	4	
27.	Have pleasant bedtime thoughts		1	2	3	4
28.	Express feelings	1	2	3	4	
29.	Use stress controls methods	1	2	3	4	

**SECTION N: HEALTH PROMOTION LIFESTYLE PROFILE (Continued)**

N2. Do you currently smoke cigarettes?

Yes \_\_\_\_\_ On average, about how many cigarettes on a  
typical day do you currently smoke? \_\_\_\_\_

No \_\_\_\_\_

N3. Do you drink alcohol (wine, beer, liquor)

Yes \_\_\_\_\_ If yes, how often do you have a drink of  
alcohol?

Daily or almost daily

Weekly

Monthly

Less than once a month

Rarely

No \_\_\_\_\_

**SECTION O: PATIENT COMPLIANCE (RHEINER, 1994)**

Please complete the following sentences with the choices listed below:

1= Always

2= Usually

3= Seldom

4=Never

1. Follow the recommendations of your doctor(s). 1 2 3 4

For "seldom or never" PROBE for barriers

---

---

2. Use drugs other than those prescribed for me 1 2 3 4  
during this period in my life.

For "always or usually" PROBE for barriers

---

---

**SECTION O: PATIENT COMPLIANCE (Continued)**

3. Objected to doing those things that are required 1 2 3 4  
in your treatment program

For “always or usually” PROBE for barriers

---

---

4. Attempted to avoid doing those things that were 1 2 3 4  
required by your treatment program

For “always or usually” PROBE for barriers

---

---

5. Missed appointments scheduled with the doctor 1 2 3 4

For “always or usually” PROBE for barriers

---

---

6. Understand your treatment program is important 1 2 3 4  
but fail to follow it.

For “always or usually” PROBE for barriers

---

---

7. Believe that your treatment program will 1 2 3 4  
increase your prospects for recovery

For “seldom or never” PROBE for barriers

---

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This concludes our questionnaire. Thank you for willingness to participate and to share this information with us.



## Consent Form

## **Spiritual-Based Counseling for African American Women with Breast Cancer**

**Principal Investigator: Diane R. Brown, Ph.D.  
Institute for the Elimination of Health Disparities**

### **Consent Form**

This consent form is part of an informed consent process for a research study and it will give information that will help you understand what the study is about and what will happen in the course of the study.

If you have questions at any time during the research study, you should feel free to ask them and should expect to be given answers that you completely understand.

After all of your questions have been answered, if you still wish to take part in the study, you will be asked to sign this informed consent form.

The study doctor, Dr. Diane R. Brown, or another member of the study team (an investigator) will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.

You understand that you are not giving up any of your legal rights by volunteering for this research study or by signing this consent form.

#### **Sponsor of the study:**

United States Department of Defense is the sponsor of this research study. The study doctor is being paid to conduct this study according to a budget that will cover the costs of the study. The costs that are usually covered include things such as: physical examinations, laboratory tests required by the study, and the costs of collecting all of the information required by the study.

#### **Why is this study being done?**

You are being asked to take part in a research study that is designed to gather information about whether spiritual counseling may improve quality of life issues for African American breast cancer survivors. The research study is being conducted at UMDNJ-School of Public Health and is being sponsored by the U.S. Department of Defense (DOD).

#### **Why have you been asked to take part in this study?**

You have been asked to participate in this study because you have been diagnosed with breast cancer and you are an African-American female, which are the criteria for enrolling in this study.

#### **Who may take part in this study? And who may not?**

Female African-American breast cancer patients between the ages of 40 and 65 may participate in this study. Potential volunteers will be screened to determine if they meet the eligibility requirements to take part in this study.

#### **How long will the study take and how many subjects will participate?**

You have been informed that the study will take place over a ten month span.

54 subjects will be enrolled in the study.

#### **What will you be asked to do if you take part in this research study?**

If you are selected to the standard care only group, you will complete interviews at three time periods, one at the beginning of the study that will take about one hour, the second seven months later, and a third three months later that will take about 30-45 minutes each. If you are selected to the spiritual-based or traditional support groups, you will complete the interviews and will also participate in seven discussion sessions, over a four month period, lasting about one hour and 30 minutes each.

You will also be asked to participate in pre-study and post-study interviews. You will be asked to complete a questionnaire which will have questions pertaining my socio-economic status, demographic information, your spiritual well-being, help seeking and decision making, and healthcare accessibility.

**What are the risks and/or discomforts you might experience if you take part in this study?**

We do not expect any injury; however you may feel some discomfort when facing issues related to your cancer or to your spiritual beliefs at a time when you are dealing with your illness. Each support group will be assigned two staff persons who are professionally trained in working with cancer support groups. The staff will be available for individual counseling if needed.

**Are there any benefits if you choose to take part in this research study?**

There may be no direct benefit to you for taking part in this study; however your participation may benefit you in coping with your cancer diagnosis.

**What are your alternatives if you don't want to take part in this study?**

You have a choice not to take part or to participate in this study. You can also take part in a regular breast cancer support group if you wish.

**How will you know if new information is learned that may affect whether you are willing to stay in this research study?**

You will be informed by the Study Doctor or staff when new information is learned that may affect whether you are willing to stay in this research study.

**Who will be allowed to look at your research records from this study?**

In addition to key members of the research team, the following people will be allowed to inspect parts of your research records related to this study:

- The Institutional Review Board (a committee that reviews research studies)
- Officials of the University of Medicine and Dentistry of New Jersey
- The study sponsor Department of Defense
- Department of Health and Human Services (DHHS) (regulatory agency that oversees human subject research)

By taking part in this study, you should understand that the study collects demographic data and data on your health. This data will be reported to the University of Medicine and Dentistry of New Jersey who will store and process your data with electronic data processing systems. The data will be kept for six years.

Your personal identity, that is your name, address, and other identifiers, will be kept confidential. You have a code number and your actual name will not be used. Only your study doctor will be able to link the code number to your name and will keep this information for six years. A breach of confidentiality is a risk; however we make every possible effort to ensure that data will not be released to anyone outside of the study.

Your data may be used in scientific publications. If the findings from the study are published, you will not be identified by name. Your identity will be kept confidential. The exception to this rule will be when there is a court order or when a law exists requiring the study doctor to report communicable diseases. In this case, you will be informed of the intent to disclose this information to the state agency. Such a law exists in New Jersey for diseases such as cancer, infectious diseases such as hepatitis, HIV, viruses and many others.

The Department of Defense will be allowed to examine the data in order to analyze the information obtained from this study, and for general health research.

In applications for marketing authorization, your data may be submitted to domestic and foreign drug regulatory agencies.

If you do not sign this approval form, you will not be able to take part in this research study.

You can change your mind and revoke this approval at any time. If you change your mind, you must revoke my approval in writing. Beginning on the date you revoke your approval, no new personal health information will be used for research. However, researchers may continue to use the health information that was provided before you withdrew your approval.

You have the right to look at your study data at your study doctor's office and to ask for corrections of any kind to any of your data that is wrong.

**Will there be any cost to you to take part in this study?**

There will be no cost to you to take part in this study.

**Will you be paid to take part in this study?**

You will receive a total of \$70.00 for taking part in this study according to the following schedule:

**Control Group A:**

- \$20.00 for completing the initial interview
- \$20.00 for completing the post interview
- \$30.00 for the completion of a follow up interview

**Control Group B:**

- \$20.00 for completing the initial interview
- \$20.00 for completing the post interview
- \$30.00 for the completion of a follow up interview

**Intervention Group:**

- \$20.00 for completing the initial interview
- \$20.00 for completing the post interview
- \$30.00 for the completion of a follow up interview

You must complete all of the interviews to receive the full \$70.00. Otherwise, you will be paid only for the interviews you complete.

**What will happen if you are injured during this study?**

There is no risk of injury in this study.

**What will happen if you do not wish to take part in the study or if you later decide not to stay in the study?**

Participation in the study is voluntary and you are free to withdraw at any time. If you decide to withdraw from the study, you will continue to receive standard care. Also, if you are uncomfortable with a question on the questionnaire, you are free to leave it unanswered.

**Who can you call if you have any questions?**

If you have any questions concerning your participation in this study now or in the future, Diane R. Brown, Ph.D., Principal Investigator, or one of her associates can be contacted at (973) 972-4382. If you have any questions regarding your rights as a research subject, you can contact the Director or Chair of the Institutional Review Board at (973) 972-3608.

**What are your rights if you decide to take part in this research study?**

You understand that you are not giving up any of your legal rights by volunteering for this research study or by signing this consent form.

You understand that you have the right to ask questions about any part of the study at any time. You understand that you should not sign this form unless you have had a chance to ask questions and have been given answers to all of my questions.

You have read this entire form, or it has been read to you, and you understand what has been discussed. All of your questions about this form and this study have been answered.

You agree to take part in this research study.

Subject Name:

---

Subject Signature:

---

Date:

Investigator Signature:

---

Date:

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## CHART II

Variables	Measures
<b>BACKGROUND AND CONTROL MEASURES</b>	
<b>Socio-Demographic</b>	
Age	Date of birth
Personal & Household Income	National Health Interview Survey (NCHS)
Education	Highest year attained
Marital status	Married, widowed, separated, divorced, never married
Employment status	Not employed/Employed - full-time or part-time
Occupation	U.S. Dept of Commerce categories
Composition of Household	List of persons in household by age, gender and relationship
<b>Religious Involvement</b>	
Denominational Affiliation	Gary, Brown et al., 1989
Non-organizational Involvement	Prayer, listen to music (Chatters & Taylor, 1994)
Organizational Involvement	Church participation (Gary, Brown et al., 1989)
Religiosity	National Survey of Black Americans
<b>Spiritual Well -Being</b>	Ellison (1983)
<b>Availability and Use of Social Support</b>	Modified Berkman & Syme Index focusing on network and support from family members: children, spouse, friends, neighbors, coworkers
<b>Sources of Stress</b>	Modified Holmes and Rahe (1967)
<b>Cancer Background and History</b>	
Stage of disease	Stage I, II, III
Date of first diagnosis	Brown & Simon, 1995
Current treatment	Brown & Simon, 1995
Functional status	Brown & Simon, 1995
Family history of disease	Brown & Simon, 1995
Comorbidities	Brown & Simon, 1995
<b>OUTCOMES MEASURES</b>	
<b>Mental Health</b>	
Depression, Anger & Anxiety	Profile of Mood States (McNair et al., 1971) CESD (Radloff, 1977)
<b>Quality of life</b>	FACT-B (Cella et al. 1993)
<b>Health-Promoting Behaviors</b>	Health Promoting Lifestyle profile (Walker et al., 1987)
<b>Treatment Compliance</b>	Rehabilitation Compliance Scale (Rheiner, 1994)

## Spiritual-Based Counseling for African American Women with Breast Cancer Recruitment Summary – Newark New Jersey

### Hospitals/Medical Centers

Breast center	Mountainside Breast Cancer Program	Recruitment flyers distributed 1/27/06
Women's Health	Mountainside Women's Health Center	Recruitment flyers distributed 1/27/06
Women's Health	Clara Maass Women's Health Center	Recruitment flyers distributed 1/27/06
Hematology/Oncology	Essex Hematology Oncology at Clara Maass	Recruitment flyers distributed 1/27/06
Radiology	Clara Maass Medical Center	Recruitment flyers distributed 1/27/06
Imaging Center	Progressive Imaging Center at Clara Maass	Recruitment flyers distributed 1/27/06
Family Care Center	St. James Hospital	Recruitment flyers distributed 2/08/06
	St. Michael's Medical Center	
Breast center	The Connie Dwyer Breast Center	Recruitment flyers distributed 2/15/06
Regional Cancer Center	St. Michael's Medical Center	Recruitment flyers distributed 2/15/06
	University of Medicine & Dentistry	
Breast center	Center for Breast Imaging	Recruitment flyers distributed 2/3/06
Radiology	Columbus Hospital	Recruitment flyers distributed 2/02/06
Center for Oncology	Columbus Hospital	Recruitment flyers distributed 2/02/06
Registry office	Columbus Hospital	Recruitment flyers distributed 2/02/06
		Recruitment flyers distributed 2/08/06
Oncology	Newark Beth Israel Medical Center	4/5/06 informed they could no longer help
	Flo Okin Oncologic Center	Recruitment flyers distributed 2/08/06
Radiology	Newark Beth Israel Medical Center	4/5/06 informed they could no longer help
Cancer Center	St. Barnabas Medical Center Cancer Center	Declined to participate

### UMDNJ

We have posted numerous study flyers throughout UMDNJ and this has only yielded 1 call. This patient was screened, is eligible and agreed to participate.

In April 2006, we began actively recruiting women through UMDNJ's cancer outpatient program. The nurse practitioner each Monday informed us when women who fit our criteria would be coming in for appointments during that week. At the clinic, the nurse practitioner first talked with the women, explained the study and obtained their verbal approval to talk with us. If the patient was willing to talk with us, she was screened, and if eligible, was told about the study. This method yielded 6 potential participants over 5 months.

### Physicians

Dr. Said Saleh	Clara Maass	Recruitment flyers distributed 1/27/2006
Dr. Hemalatha Vasireddy	Clara Maass	Recruitment flyers distributed 1/27/2006
Dr. John Conti	Clara Maass	Recruitment flyers distributed 1/27/2006
Dr. Alan Lippman	Clara Maass	Recruitment flyers distributed 1/27/2006
Dr. James M. Orsini	Clara Maass	Recruitment flyers distributed 1/27/2006
Dr. Patrick DiPaolo	Mountainside	Recruitment flyers distributed 1/27/2006
Dr. Robert Zager	Mountainside	Recruitment flyers distributed 1/27/2006

Dr. Charles Sagorin	Mountainside	Recruitment flyers distributed 1/27/2006	Yielded no call
Dr. Eric Whitman	Mountainside	Recruitment flyers distributed 1/27/2006	Yielded no call
Dr. Michael Kane	Mountainside	Recruitment flyers distributed 1/27/2006	Yielded no call
Dr. Nancy Elliot	Mountainside	Recruitment flyers distributed 1/27/2006	Yielded no call
Dr. Kathleen Ruddy	Clara Maass	Recruitment flyers distributed 1/27/2006	Yielded 1 call
Dr. Nadine C. Pappas	Clara Maass	Recruitment flyers distributed 1/27/2006	Yielded 1 call
Dr. Margarette R.N. Bryan	UMDNJ	Recruitment flyers distributed 2/3/2006	Yielded no call
Dr. Alice Cohen	Beth Israel	Recruitment flyers distributed 2/8/2006	Yielded no call

## Mammography Centers

New Jersey Open MRI	Newark	Recruitment flyers distributed 2/20/2006	Yielded no calls
South Mountain Imaging Center	Milburn	Recruitment flyers distributed 2/20/2006	Yielded no calls
Montclair Radiology	Montclair	Recruitment flyers distributed 2/20/2006	Yielded no calls
St. James Hospital Diagnostic Radiology	Newark	Recruitment flyers distributed 2/20/2006	Yielded no calls
UMDNJ-Imaging Center	Newark	Recruitment flyers distributed 2/20/2006	Yielded no calls
Progressive Imaging Center at Clara Maas	Bellville	Recruitment flyers distributed 2/20/2006	Yielded no calls
Magnetic Resonance of NJ, P.A.	Nutley	Recruitment flyers distributed 2/20/2006	Yielded no calls
Montclair Radiology Associates, P.A.	Nutley	Recruitment flyers distributed 2/20/2006	Yielded no calls
North Essex Imaging	Newark	Recruitment flyers distributed 2/20/2006	Yielded no calls
St. Joseph's Hospital and Medical Center	Patterson	Recruitment flyers distributed 2/20/2006	Yielded no calls
St. Barnabas Outpatient Center	Livingston	Recruitment flyers distributed 2/20/2006	Yielded no calls
St. Joseph's Regional Med. Ctr. Ambulatory Imaging Ctr.	Clifton	Recruitment flyers distributed 2/20/2006	Yielded no calls
Clifton Medical Center	Clifton	Recruitment flyers distributed 2/20/2006	Yielded no calls
Clifton Medical Imaging Center	Clifton	Recruitment flyers distributed 2/20/2006	Yielded no calls
Diagnostic Imaging of Clifton, P.A.	Clifton	Recruitment flyers distributed 2/20/2006	Yielded no calls
Allwood Imaging	Clifton	Recruitment flyers distributed 2/20/2006	Yielded no calls

## Churches

Contacted	Health Ministry	Women's Ministry	Faxed Information	Mailed Information	Emailed Information	Follow -up	Presentation scheduled	
17	6	14	11	5	1	3	3	Yielded no subject

Although churches voiced an interest, making contact with either the head of the Health or Women's Ministry group was difficult. It was difficult because we could not get phone contact information for the group leaders due to the fact that it was their home number and church leaders were not willing to give that out. They would pass our information on but it would dead end there even with repeated calls/faxes.

## Pharmacies

We contacted pharmacies in Newark, East Orange, Irvington, Bloomfield and Montclair asking permission to have our study flyer.

Contacted	Agreeing to post flyer	Flyers posted	
50	27	27	Yielded no calls

## Media

- o Television
  - o
    - Cablevision local channel programming
      - \_ Dr. Brown taped a PSA 12/16/05 which aired in February
      - \_ Yielded no calls
- o Press release
  - o
    - UMDNJ media relations staff Kaylyn Dines produced a press release (DOD IRB approved UMDNJ IRB approved)
    - UMDNJ media relations staff Kaylyn Dines distributed press release in early March.

- Received one call from a woman who read about the study in her Local Talk Newspaper. She was eligible and agreed to participate
- o Magazines
  - UMDNJ media relations staff Kaylyn Dines got *Positive Community*, a church and community magazine to print a half page story about the study.
  - Yielded no calls